

**SWIMMING UPSTREAM:
THE EXPERIENCE OF PARENTS WHO CHOOSE NOT TO
IMMUNIZE THEIR CHILDREN**

by

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Abstract

This study explored the experience of parents who have chosen not to immunize their children. Immunization is generally considered by health care professionals to be one of the most effective public health practices. There is an assumption in the immunization literature that if parents choose not to immunize their children then they must need more information, or they do not understand the risk of disease or they are following some incorrect line of reasoning. An interpretive descriptive design was used for this study of nine parents who had declined immunization for their children. Participants ranged in age from 25 to 45 years, with children ranging in age from 4 months to 12 years. All parents resided in the catchment area served by the Vancouver Island Health Authority – South Island. Data were collected by unstructured interviews and analyzed using inductive analysis. Parents reported that they sought to be well informed, they desired expert advice and they found themselves weighing conflicting choices and opinions. Parents also reported varying degrees of support from health care providers and others after making a socially unacceptable decision. And finally, parents reported their experience of learning to live with the repercussions of their decision including their perception of health care received and accessing health care services. The findings from this study have the potential of assisting health care providers to have a better understanding of the experience of parents who decided not to immunize, and how their practice potentially affects the experience of parents.

Table of Contents

Abstract	ii
Table of Contents	iii
Dedication	vi
Acknowledgements	vii
Chapter 1 : Introduction	1
Background to the Problem	1
Purpose of Study	6
Significance of the Research	7
Chapter 2 : Literature Review	9
Factors Influencing Immunization Decision-Making	10
Susceptibility to the Disease	11
Seriousness of the Disease	12
Benefits of Prevention and Disease	13
Risk Communication	15
Vaccine Safety/Side Effects	17
Religious Beliefs	19
Community Benefit	20
Political Dimension	20
Heuristics	21
Cues to Action	24
Reminder/Recall	24
Media Influence	25
Educational Strategies	26
Professional Advice to Parents	27
Lay Advice to Parents	28
Demographic and Socio-Psychological Variables	29
Parenting and Valuing of Parental Expertise	31
Parenting	31
Decision-Making in Children's Health	33
Health Care Provider/Parent Relationships	36
Summary	38
Research Question	39
Definition of Terms	40

Chapter 3 : Methods	41
Research Design	41
Participants	42
Participant Recruitment	42
Inclusion/Exclusion Criteria	44
Description of the Sample	45
Data Collection Procedure	46
Data Analysis	48
Rigor	50
Ethics and Human Rights Considerations	53
Informed Consent	54
Confidentiality	54
Limitations of the Study	55
Potential Significance of the Study	55
Chapter 4 : Research Findings	57
Seeking to be Informed	57
Searching for Information	58
Accessing Information	60
Neutrality of Information	64
Questioning the Establishment	66
Desire for Expert Advice	70
Credibility of Health Care Providers and Their Advice	71
Maintaining the Status Quo	76
Making a Decision Not to Immunize	78
Seeking to be Supported	80
Feeling Supported	81
Feeling Unsupported	85
Strategies for Supportive Interactions	92
Seeking to Have the Decision Accepted	96
Questioning the Decision	96
Taking Responsibility	98
Perception of Care and Access to Services	100
Summary	102
Chapter 5 : Discussion of the Findings	104
Parental Expertise and a Decision not to Immunize	105
Trust in Varying Degrees	111
Communication and Power in Health Care Relationships	118
Summary	126

Chapter 6 : Implications for Nursing	130
Implications of the Study	131
Implications for Nursing Practice	132
Implications for Nursing Education	135
Implications for Research	136
Implications for Policy/Program Development	138
Personal Perspectives	139
Conclusion	140
References	142
Appendices	
Appendix A: Letter of Invitation to Participate	153
Appendix B: Demographic Information	156
Appendix C: Interview Guide	158
Appendix D: Consent Form	161

Dedication

This work is dedicated with deep love and thankfulness to Wayne, Peter and
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Chapter 1

Introduction

The success of infant and childhood immunization programs is heralded as one of the most effective health interventions of the 20th century and is credited with a substantial portion of the overall increase in life expectancy in this period. According to a World Health Organization (WHO) estimate, “immunization saves three million lives in the world every year and another three million could be saved if gaps in funding, research and immunization coverage were closed” (“Global Immunization,” 2003, p. 9). With the exception of availability of clean drinking water, it is reported that no other human undertaking can equal the impact immunization has had on reducing infectious disease mortality rates, not even antibiotics (Bedford & Elliman, 2000). A number of parents, however, choose not to vaccinate their children. Immunization experts agree that one of the significant contributors to concerns and confusion that surround immunization is, ironically, its own overwhelming success (Ulliyott, 2000).

Background to the Problem

Immunization¹ has been seen as an acceptable and expected standard of childhood health care by health professionals and many parents. Data collected for the Canadian Public Health Association indicate that 92% of Canadian parents believe it is important that their children be vaccinated (Martin, 2002). Immunization has been shown to be effective in preventing childhood diseases. For example, “high levels of childhood immunization coverage and global-

¹ Immunization – protection of susceptible individuals from communicable disease by administration of a living modified agent, a suspension of killed organisms, or an inactivated toxin (Last, 1995).

targeted efforts have eradicated smallpox, eliminated polio from the western hemisphere and made remarkable gains in the global effort to eradicate polio” (Halperin, 2000, p. 62). In Canada, a permanent drop in measles occurred with the introduction of measles vaccine in 1963 (British Columbia Centre for Disease Control, 2001) and Haemophilus influenza b (Hib) cases in Canada reduced following the introduction of vaccine from about 2000 per year in 1988 to only 26 in 1996 (Health Canada, 1998).

In 1985 the WHO set an immunization target level of almost universal vaccination coverage by the year 2000 (WHO, 1985). That same year, the United Kingdom (U.K.) suggested immunization targets to reach 90% by 1990 (Bennett & Smith, 1992). Data indicates the U.K. target was not met (Nicoll, Elliman, & Begg, 1989) and the WHO target became increasingly unrealistic as immunization rates began to slow. In 1997, a survey of immunization programs in British Columbia (B.C.) showed that over 90% of children completed the recommended vaccine series by 24 months of age. On closer examination, however, the recommended schedule of immunizations was not consistently followed. Almost all children began on schedule, but with each subsequent dose, became less and less timely (BC Ministry of Health, 1997).

The current environment in which parents are making immunization decisions is substantially different from the early days of vaccine-preventable disease immunization. In the early days, immunizations were offered as single

components (monovalent²), often associated with outbreaks³, but always within the context of disease knowledge. The experience of parents in those early days was often reported as relief that medicine was available to spare children's lives from epidemics⁴ which ravaged whole countries. A snapshot impression would name fear as a significant motivating factor for immunization during such epidemics. Today, immunization programs continue to depend, in part, on those early experiences, which may not be part of the reality for some of today's young parents. Parents today may lack first hand knowledge of the effects that vaccine-preventable diseases have had or are having in developing countries. Even measles outbreaks in the past decade that have occurred in developed countries such as Hong Kong and The Netherlands have had little impact on global immunization trends (Chuang et al., 2002; van den Hof, Conyn-van Spaendonck, & van Steenberghe, 2002). Halperin (2000) states that "with the disappearance of these once common and deadly diseases, many young adults of child-bearing age no longer have first-hand experience of these illnesses, and, therefore, have not learned to fear them" (p. 62).

Parents making immunization decisions today are faced with many more variables beyond the fear of vaccine preventable disease. For example, with increased numbers of vaccines available and recommended by health authorities, the infant immunization schedule is becoming crowded. In 2003

2 Monovalent vaccine refers to biological product provided as a single antigen component vaccine such as polio vaccine, in contrast to vaccine containing more than one antigen, such as tetanus-diphtheria-polio vaccine.

3 Outbreak –an epidemic limited to localized increase in the incidence of a disease, for example in a village, town or closed institution (Last, 1995)

4 Epidemic – the occurrence in a community or region of cases of an illness, specific health-related behavior, or other health-related events clearly in excess of normal expectancy (Last, 1995).

alone, two new vaccines have been added to the B.C. immunization schedule in addition to the 3 vaccines already included. This translates into eleven vaccine components in total being offered in the infant immunization program (B.C. Centre for Disease Control, 2003).

Reports of vaccine-related injury can also influence parental immunization decision making. Conditions such as autism, attention deficit disorder, diabetes, multiple sclerosis and Alzheimer's disease are frequently cited in the media and popular literature as having possible links to immunization (Diodati, 2000b; Megson, 2000). Parents' fears of vaccine related side effects and concerns about vaccine safety have also been reported and have been found to influence immunization decision making (Bennett & Smith, 1992; Bentsi-Enchill & Duclos, 1997; Bond, Nolan, Pattison & Carlin, 1998; Meszaros et al., 1996; Prislin, Dyer, Blakely & Johnson, 1998; Roberts, Sandifer, Evans, Nolan-Farrell, & Davis, 1995; Shawn & Gold, 1987; Tarrant & Gregory, 2001). Studies have demonstrated that parent's decisions to immunize may also be influenced by perceptions of vaccine effectiveness and the benefits of natural disease. Some parents report vaccine to be sometimes or never effective (Blair, Shave & McKay, 1985). In addition, a strong anti-vaccination and homeopathic movement has proposed alternate strategies to parents for protecting their children against disease and infection (Bedford & Elliman, 2000). Thus, today's parents are now faced with several factors to consider when making immunization decisions for their children.

A text that includes a chapter on parenting states that a parent has a “duty to protect” a child (Kegan, 1994, p. 90). While a parent is expected to make decisions in the child’s best interests, a decision to immunize or not immunize is not accepted easily as a simple decision. Even though immunization has been shown to prevent or eliminate disease, there are an increasing number of parents who choose not to immunize their children (Halperin, 2000). These decisions, however, are being made within the context of strong societal pressures to immunize (Parkman, 2002). The context in which today’s parents are making immunization decisions is one in which immunization is the norm. The following statement published in a recent B.C. provincial health guide is indicative of the current context: “If you are considering not having your child immunized, talk with your health professional. There are few valid reasons for not having your child immunized” (Kemper, 2000, p. 17).

Immunization is generally considered by health care professionals to be one of the most effective public health practices. Therefore, immunization has become an expected practice with most health care professionals encouraging parents to immunize their children. Nevertheless, the trend of immunization rates has remained below national targets, with an increasing number of parents making the decision either not to immunize or to partially immunize their children (Health Canada, 2002a). Health care providers are becoming increasingly concerned about parents opting not to immunize (Halperin, 2000; Martin, 2002). They argue that if all vaccine-preventable diseases were confined to the individual, such as tetanus, the consequences of foregoing vaccination would fall

only on the child whose parents made the decision. Most vaccine-preventable diseases, however, are spread from person to person. Therefore, the health of any individual in the community is intricately dependent on the health of the rest of the community. Until vaccines become available that are 100% effective or a disease is eradicated, an increase in exemptors has the potential to precipitate community-wide outbreaks of vaccine-preventable diseases (Oostvogel & van Wijngaarden, 1994). Thus, the tension between protecting public health and allowing individual autonomy is a key issue underlying immunization.

Purpose of Study

More parents are making decisions to not immunize their children. A typical response by health care professionals to this decision is to educate parents on the benefits of immunization (Prislin et al., 1998). Studies indicate that health care professionals believe that with better education and information, parents who have chosen not to immunize their children will change their minds (Prislin et al., 1998). However, research suggests that parents who are provided with information supporting the value and safety of vaccine tend to be more convinced of their original decision, whether that is for or against vaccination⁵ (Meszaros et al., 1996).

Sometimes health professionals judge parents against their own standard of 'reasonable behaviour' which in the case of vaccine-preventable disease, is to immunize. A widely accepted assumption in nursing and other health professions is that, given knowledge and evidence, people will change their health patterns in

⁵ Vaccination – originally vaccination referred to inoculation with vaccinia virus against smallpox, recently the word is broadly used synonymously with procedures for immunization against infectious disease (Last, 1995).

ways conducive to health (Pilkington, 1997). While health professionals generally recognize that persons are free to 'take or leave' any advice they are given, so entrenched is the belief that knowledge will produce change that it is considered anomalous when change does not occur.

Little research has been done to understand the perspective of parents who choose not to immunize their children. It is assumed, primarily by health professionals, that parents are not informed or they are not well educated on the potential consequences of their decisions (Blair et al., 1985; Dalphinis, 1986). Well it may be that some parents do not possess all of the information needed to make informed immunization decisions, the experiences of these parents is not well understood. Therefore, the overall purpose of this study was to gain a better understanding of the experience of parents who made a decision not to immunize their children, and to describe how their decision was interpreted by others.

Significance of the Research

There is an assumption in the immunization literature that if parents choose not to immunize their children then they must need more information, or they do not understand the risk of disease, or are following some incorrect line of reasoning (Health Canada, 2002b; Hinman, 2000). Nevertheless, health professionals have a responsibility to provide a standard of care which is unaffected by a parental decision not to immunize. Findings from this research study have the potential to assist health care providers in gaining a better understanding of the experience of parents who decide not to immunize, and

how their practice potentially affects the experience of parents. Such information could provide the basis for informing interventions to support parents in whatever decision they make.

We have little information of the experience of parents, but given strong societal expectations and expectations of the health care system to immunize, it is imperative to understand what parents experience when they make a decision not to immunize. In this way, we will have a better understanding of how to develop interventions to support parents not only once the decision is made, but also during the decision-making process.

Chapter 2

Literature Review

To determine the current state of knowledge, this review examined the literature pertaining to parental attitudes regarding childhood immunization and the factors involved in parental immunization decision-making. In particular, research literature was reviewed regarding immunization decision-making, perceptions of vaccine-preventable diseases and vaccines, risk communication, socio-demographic characteristics in relation to immunization uptake, and parental health care decision-making. Several research studies were found to be useful in examining influences on immunization decision-making and patterns of vaccination acceptance. A review of the non-research literature was also useful to examine risk communication, the relationship between knowledge and patterns of health behaviour, parenting, and parental health care decision-making in relation to chronically ill children.

The literature search was accomplished through various means. The search began using Medline and CINAHL (Canadian Index of Nursing and Allied Health Literature). The reference lists from two key articles were used to assist in the search process, yielding many more relevant studies. The Canadian Journal of Public Health, Canadian Medical Association Journal, the American Journal of Public Health, the British Medical Journal, the New England Journal of Medicine, and the Journal of Infectious Diseases were all hand reviewed for the years 1992 to present. The Bulletin of the WHO and the Paediatric Child Health Journal were hand reviewed for the years 1996 to present. Several Internet web-sites

pertaining to immunization were reviewed including those of the WHO, United States Communicable Disease Control (CDC) and Health Canada.

Although there have been several studies of immunization uptake and decision-making in developing countries, this review considered studies which looked at immunization decision-making in developed countries. Studies which consider patterns of vaccination acceptance in developing countries were not informative for this literature search because the factors that lead to non-acceptance of immunization differ immensely from the experience of the western world and are heavily dependent on socio-cultural and political contexts⁶. Therefore, for the purpose of this review, literature from developed countries was considered.

The literature review is organized under four main areas. First, I reviewed studies examining the factors that influence parents' decision making about immunization. Second, I examined cues to action⁷. Third, I considered demographic and socio-psychological variables that influence immunization decision-making. Finally, I considered parenting and valuing of parental expertise.

Factors Influencing Immunization Decision-Making

The literature suggests there are several factors that influence immunization decision-making. They are: 1) Susceptibility to the disease; 2) Seriousness of the disease; 3) Benefits of Prevention and Disease; 4) Risk

6 For example, Streefland, Chowdhury, and Ramos-Jimenez (1999) found that mother's question the need for vaccination due to organized resistance movements within local political strife or social resistance movements.

7 A cue to action is a signal or indirect suggestion which guides behavior (Webster, 1976)

Communication; 5) Vaccine Safety/ Side Effects; 6) Religious Beliefs; 7) Community Benefit; 8) Political Dimension; and 9) Heuristics.

Susceptibility to the Disease

Perception of susceptibility to disease has been considered in several studies and may be an important factor for some parents in immunization decisions. Dalphinis (1986), in a small quantitative survey of immunization defaulters in the U. K., found that some parents believed their children were less vulnerable to disease due to advanced medical technology. Other studies such as one by Bennett and Smith (1992) demonstrated that non-immunizers reported a greater perceived risk of their child developing the vaccine-preventable disease if they were vaccinated. Similarly, in large quantitative surveys of the socio-psychological factors affecting infant immunization, Markland and Durand (1976) and Woodruff, Unti, Coyle and Boyer-Chuanroong (1996) demonstrated that parents of inadequately immunized or non-immunized children had a low perception of their children's susceptibility to disease. In a recent study of influenza illness and immunization, Grant et al. (2003) reported that "forty percent of the parents of non-immunized children felt that their children were not at risk of disease" (p. 40). Conversely, Rosenblum, Stone and Skipper (1981), in a descriptive correlational study of mothers of preschool children, investigated the difference in perception of disease susceptibility between vaccinating and non-vaccinating mothers and concluded that there was no significant difference.

The question of perceived susceptibility in relation to age of the child has also been studied. Le, Jones, and Schwarz (1986), in a retrospective quantitative

study of immunization levels in toddlers, reported a reduction in immunization levels between the ages of one year and preschool. The conclusion drawn by the authors was that toddlers are seen as less susceptible to disease than infants. Bond and colleagues (1998) found that the age of the child and the state of the child's health influenced mothers' perceptions of susceptibility and, therefore, influenced their decisions about immunization. The very young were not perceived as being at risk of exposure to serious disease and the mothers in this study were generally unaware that these diseases were often more serious for very young children (Bond et al.). Roberts and associates (1995) undertook a descriptive quantitative study using questionnaires to investigate reasons for poor immunization uptake. Similar to Bond and colleagues, they found that older children were perceived to be less vulnerable to infections than infants.

Seriousness of the Disease

The overwhelming success of immunization programs is often cited as a contributing factor to the lack of acknowledgement of the potential seriousness of childhood diseases. Throughout the literature there are numerous examples reported of parents who are misinformed or lacking information about vaccine-preventable diseases. In the Bond et al. (1998), Markland and Durand (1976) and Woodruff et al. (1996) studies, parents of partially immunized or unimmunized children reportedly had a low perception of disease seriousness. Serious diseases were defined as those that were life threatening, chronic, or had long-lasting effects, and in all cases, children were considered unlikely to get any of these. Dalphinis (1986) found that a large portion of her study participants

knew very little about vaccine-preventable diseases or thought the diseases were not serious:

Almost everyone (94 percent) had heard of measles, over three-quarters of the sample (77.4%) did not think measles was serious and almost half (48.8%) did not think pertussis was serious. Half did not know anything about diphtheria (51.8%), and one-third did not know anything about tetanus (42%) or polio (38.8%) (Dalphinis, 1986, p. 343).

Similarly, a large (n=719) study described by Lochhead (1991) reported that poor understanding and disbelief by parents about the seriousness of communicable diseases influenced their decision making about immunization. Blair and colleagues (1985) also found 'serious misconceptions' with regard to symptoms and possible complications of measles and effectiveness of vaccine in preventing measles.

Benefits of Prevention and Disease

Parent's perceptions of the benefits of prevention and disease are reported as influencing immunization uptake. Parent's decisions to immunize or not immunize their children may be influenced by both the degree to which parents believe vaccines to be effective and also a belief that contracting a particular disease may be of some benefit.

The perception of the benefit of prevention in the form of immunization can be influenced by how effective parents perceive vaccine to be. For example, some studies suggest that parents may not perceive immunization to be effective in protecting their children (Blair et al., 1985). Blair and colleagues found a

substantial majority (63%) of parents reported that immunization was only sometimes or never effective. Bennett and Smith (1992) also reported that non-immunizers indicated a lower perceived benefit from vaccination than immunizers. Tarrant and Gregory (2001), in a qualitative study in two First Nations communities, found parents doubted the effectiveness of vaccines since children caught vaccine-preventable diseases despite being immunized. Although this study provides a more detailed contextual understanding of parents' experiences, the first Nations cultural context may limit the applicability of the study findings across all populations.

The perception of the benefits of immunization can also be influenced by parents' perception of the benefits of disease in its natural form. Bond and colleagues (1998) found, for example, that while serious diseases like polio or diphtheria are best avoided, prevention was sometimes not desirable to respondents. Exposure to some diseases was considered beneficial for children to 'build up' immunity. For diseases that were not considered serious, and especially where vaccines were not considered effective, respondents perceived that it was equally beneficial to either contract the disease or vaccinate (Bond et al.).

One of the main arguments found in the non-research literature and used by anti-vaccinationists is that disease provides protection by an immune response that far outweighs the protection provided by vaccine. The anti-vaccinationists state that the natural immune response to disease challenges the body in a positive way while providing long-term, stronger immunity than vaccine

(Diodati, 2000a; Scheibner, 1999). This view also includes the position that childhood diseases are mild and natural and should not be feared or interfered with. Canadian anti-vaccinationist Catherine Diodati (2000a) states, “anybody who remembers measles from their childhood knows that it is a mild disease” (p. 1). These beliefs, however, have not been substantiated with research.

Risk Communication

Risk communication⁸ has been shown to influence immunization decision-making of parents. For example, parents have reported varying experiences and levels of risk communication about disease and vaccine. The experiences include lack of, incomplete, or adequate risk communication. Blair et al. (1985), in a quantitative study of parents' awareness of symptoms and possible complications of measles reported that 50 percent of the parents did not remember talking to a health care professional about immunization. In terms of knowledge about disease, many had learned about the illness only by seeing it within their own families. This study reported a significant lack in effective risk communication with parents regarding immunization, resulting in doubt and serious misconceptions about disease. The lack of effective risk communication took the form of either not having had any discussion with health professionals or discussion which was reportedly not integrated by parents.

Bond et al. (1998), in a qualitative study of mothers' perceptions of disease and immunization found that in order to make good decisions about immunization, mothers needed to be well informed. Findings suggested that the

⁸ Risk Communication is seen as an interactive process of an exchange of information and opinion among individuals, groups and institutions, which addresses the experiences, beliefs, values, and attitudes of message recipients as well as providers.

information available to mothers was neither convincing nor comprehensive. Bond and colleagues reported that often health practitioners dismissed parents' questions and concerns, contributing to beliefs that the parents' role in the decision to immunise was not treated seriously. Similarly, Le and associates (1986) found that health care providers did not communicate to parents the importance of the timeliness of immunizations to ensure their child's protection from disease.

Effective and comprehensive risk communication, when it occurs, does not always result in a decision to immunize. Meszaros et al. (1996) utilized a quantitative methodology to randomly select 500 subscribers of *Mothering* magazine to examine the decision-making that leads some parents to forego vaccination. Interestingly, when non-vaccinators were presented with the kind of risk-benefit information that leads many medical and public health experts to conclude that the risks of vaccine are significantly less than the risks of disease, they became even more committed to non-vaccination. Meszaros and colleagues reported that parents in both the vaccinators and non-vaccinators groups focused on the evidence that strengthened their previous views. Consequently, no changes in vaccination decisions were noted. As Meszaros and colleagues demonstrated, not all parents make their decisions by weighing the risks and benefits of immunization.

There is an assumption inherent in much of the risk communication literature that parents who receive adequate information and adequate opportunity to ask questions will immunize. In a recent Vancouver-Richmond

Health Board survey aimed at examining parental opinions and acceptance of a new universal infant Hepatitis B program, the authors state that provider and parent's lack of awareness was the most common cause for children not receiving the Hepatitis B vaccine (Dawar et al., 2002). Dawar and colleagues concluded that Hepatitis B vaccine uptake can be improved by increased awareness among physicians and parents.

Vaccine Safety/Side Effects

Concern about vaccine safety and side effects has been shown to influence parents' decision to immunize their children. Research on this issue seems to belong in one of two distinct bodies of literature including studies measuring the presence or absence of safety/side effect concerns and studies exploring the phenomenon of parental anxiety associated with safety/side effect concerns.

Studies addressing presence or absence of safety/side effect concerns have shown that parents' refusal to vaccinate is likely linked to vaccine product safety and beliefs about contraindications (Bentsi-Enchill & Duclos, 1997; Prislin et al., 1998). Parental concern about vaccine safety has been found to be the most significant predictor of non-vaccination (Bennett & Smith, 1992; Bond et al., 1998; Meszaros et al., 1996; Roberts et al., 1995; Shawn & Gold, 1987). In the Meszaros et al. study, non-vaccinators were found to have a dramatically different idea than vaccinators about the probability of serious vaccine side effects. Ninety percent of non-vaccinators believed their child was more likely to have serious long-term injury from vaccine than from disease (Meszaros et al.).

A qualitative exploration of knowledge, experience, and concern of childhood diseases and immunizations by White and Thomson (1995) in New Zealand demonstrated an interesting cross-cultural comparison of vaccine safety concerns. New Zealand born parents who had limited first-hand knowledge and experience of childhood diseases were more concerned about the perceived safety of the vaccines than about the childhood diseases. In contrast, parents who grew up in the Pacific Islands and had first-hand knowledge of the overt sequelae of childhood diseases, were less concerned about the safety of vaccines. Incidental cross-cultural differences have been noted, but overall, the study reflects a greater concern about the side effects of immunization than about the side effects of childhood diseases (White & Thomson).

Parental anxiety and the impact on immunization uptake has also been studied. Shawn and Gold (1987) explored parents' attitudes to a recommended vaccine program and found the fear of vaccine side effects was a major concern of parents. Fear was much more common among those parents who did not have their child vaccinated. The fear expressed took the form of anxiety about the possibility of short-term side effects encountered with vaccines and unknown complications that might appear years later (Shawn & Gold).

Direct and indirect personal experience with vaccine attributed side effects has been shown to play a role in parental immunization decision-making. Bond and colleagues (1998) found, for example, that non-immunizers perceived vaccines to be ineffective in preventing disease and to be harmful. Parents in this study reported vaccine side effects to be upsetting and resulted in them delaying

further immunizations or discontinuing vaccinations altogether, although, the experience of side effects, even severe side effects, was usually only one factor out of many which contributed to the decision to discontinue vaccination (Bond et al.). Participants in the Tarrant and Gregory (2001) study reported 'stories' of negative sequelae from immunizations that circulate in their communities having a negative impact on vaccination uptake.

Religious Beliefs

Depending on the composition of the local faith community and specific religious group's views of conventional medicine, religious beliefs have been found to influence immunization rates. Religious beliefs were the second most common reason found by Simpson, Lenton and Randall (1995) for parents' decision not to immunize their child. In this study, the beliefs of the Christian Science Church were cited which includes the view that healing is a natural result of drawing closer to God and, therefore, immunizations are not necessary. Although the Christian Science Church is reported to support any family who seeks conventional medical care, some families applied church teaching to immunization and refusing immunization as well (Simpson et al.). In the Netherlands there are large pockets of resistance to vaccination within a society with a promotive vaccination regime, such as Orthodox Protestants and New Age followers whose vaccination resistance behaviour is based on religious convictions. Similar findings were reported by a recent Canadian study in Southwest Alberta. In this qualitative investigation, Kulig and colleagues (2002) reported refusal to immunize among the people of Dutch ethnic background was

based on religious beliefs.

Community Benefit

Only a few studies were found that examined whether the benefits to the larger community influenced parental decision-making about immunization. One study reported a small number (6%) of participants were primarily concerned with protecting the community by preventing the spread of disease (Kilmartin, Woodward, Blizzard & Turner, 1998), although this study was done in Southern Tasmania where culture may dictate community responsibility. Bond and colleagues (1998) reported that “complete and incomplete immunizers recognized that immunising helped protect others in the community” (p. 443), but the impact on immunization decisions was not reported.

A report documenting the last outbreak of polio in the United States (in 1979) found that about 75% of children in the religious community affected were vaccinated (Hinman, 2000). “Although their parents did not support vaccination to protect themselves or their children, they were willing to be vaccinated in order to provide protection to the community at large” (Hinman, p. 249). Thus, it appears that community benefit may have some influence on immunization decision-making.

Political Dimension

The political dimension of immunization is receiving increasing attention as the public question the motivation of government decision-making. In White and Thomson’s (1995) qualitative study, interviews with parents demonstrated that parents may be suspicious of government agendas. Parents felt that mass

immunization campaigns were a 'cop out' for not improving poor socio-economic conditions. In general, parents' perceived government as being driven by political considerations rather than by concerns for health. Parents' beliefs affected their decision to have their child immunized in that those who believed government promotion of immunization was motivated by a political agenda did not immunize their child, even if they felt the vaccine was safe (White & Thomson).

Heuristics

Heuristics are cognitive shortcuts that some people use to simplify complex decisions and judgements (Ball, Evans, & Bostrom, 1998). Several authors contend that heuristics influence immunization decision-making. For instance, omission bias is a heuristic that involves not doing an action. In the case of immunization decisions, an act of omission is not vaccinating. It has been argued that omission bias is an error in decision-making for it fails to produce the best possible consequences (Ritov & Baron, 1990), that is, to vaccinate.

Meszaros et al. (1996) and Ritov and Baron found that non-vaccinators prefer acts of omission over acts of commission. For example, Meszaros & colleagues found that non-vaccinators reported feeling more responsible for an adverse outcome caused by a decision to immunize than for the same outcome caused by the disease after withholding vaccination. Similarly, Ritov and Baron found that some individuals feel more responsible if their child died after a vaccination than after a vaccine-preventable disease.

Ambiguity aversion is another heuristic that has been shown to influence immunization decision-making (Meszaros et al., 1996). Ambiguity exists when

the probability of an event happening is not known for sure. People are averse to options with ambiguous outcomes in a variety of contexts including the case of an immunization event. Given a choice, individuals tend to avoid ambiguity (Baron, 1994). For example, a risk from a known disease may be more acceptable than an equivalent or smaller risk that is perceived as more ambiguous, such as from a new vaccine (Ball et al., 1998). Skepticism of some parents about scientific and medical information may increase their sensitivity to ambiguity compared to other parents. This phenomenon was evident in the Meszaros et al. study. Skepticism about medical information related to vaccines was significantly higher for non-vaccinators and ambiguity aversion was also significantly higher for non-vaccinators. Although ambiguity aversion is not discussed frequently throughout the literature, issues such as fear of side effects, susceptibility to disease, seriousness of disease, and safety of vaccines all potentially involve ambiguity aversion.

Herd immunity refers to the protection from disease which exists in a community or group of people when most or all of the members are immunized. Free-loading or free-riding refers to the benefit an individual derives from living in a community or group where most or all members are immunized. It is thought that an individual who is not immunized who lives in such a community is protected from the vaccine-preventable disease by its absence (Hershey, Asch, Thumasathit, Meszaros & Waters, 1994). A single unvaccinated child in a community of vaccinated children holds strategically opportunistic high ground, protected from risk of disease by herd immunity while avoiding risk of adverse

events associated with vaccination. Some parents who withhold vaccinations may use freeloading logic, relying on high vaccination rates and herd immunity to protect their unvaccinated child (Ball et al., 1998; Hershey et al.). Herd immunity is not found frequently in the research literature as a rationale not to immunize. However, one study found that recognition of the free-riding potential is significantly higher for non-vaccinating parents (Meszaros et al., 1996).

Finally, band-wagoning or "following the crowd", has also been linked to immunization decision-making. In immunization, band-wagoning is the tendency for parents to vaccinate if "everyone else is doing it," without fully evaluating the options themselves. This factor was mentioned in the non-research literature as a determinant of immunization (Ball et al., 1998), and in a study by Hershey et al. (1994) who tested the hypothesis that some individuals make vaccination decisions by simply "jumping on the bandwagon" (p. 178). Using multiple regression analysis, the researchers reported that the propensity to vaccinate increases as the percentage of others vaccinating increases. This tendency may also apply to decisions not to vaccinate, as there are geographic pockets with larger than average rates of non-vaccination.

In summary, factors that influence parental immunization decision-making vary widely. Most of the studies in this area use quantitative methodologies and few studies focus on the actual experience of parents making immunization decisions. Findings from many of the studies to date, show inconsistent results, and provide only a cursory overview of the context in which immunization decision-making occurs.

Although vaccine safety appears to be the most thoroughly studied concept in the immunization literature, few studies report on how parents integrate this knowledge and other forms of knowledge into their decision-making about immunization. Another frequently studied concept was parents' perception of vaccine effectiveness, but little evidence linking this perception to immunization decisions was reported. A cursory overview of factors such as cognitive, socio-political, religious, and community, perceived to influence immunization decision-making, appeared in the immunization literature. However, the nature of these influences and the experience of parents making immunization decisions remains an understudied topic.

Cues to Action

A cue to action⁹ can be either internal or external. Examples of internal cues include previous experiences with immunization of another child according to accepted schedules. External cues may include, for example, reminder/recall notices, media communications, educational strategies, and advice from others. Each of the external cues mentioned above were found in the research literature and identified as potentially important in parents' experience with immunization decisions.

Reminder/Recall

Reminder/recall notices may be important as a 'cue to action' for parents in relation to immunization. Lack of motivation of parents to follow through on intentions to immunize was found to be a contributing factor in vaccination compliance. Shawn and Gold (1987) found, for example, that although parents

9 A Cue to action is a signal or indirect suggestion which guides behavior (Webster, 1976)

indicated their intention to have their children vaccinated, one third of study participants required a telephone reminder before they had their children vaccinated. Similarly, Kilmartin and associates (1998) found that over 90 percent of respondents in their study needed to be reminded when their baby's next immunization was due. As an extension of the Le et al. (1986) study, an informal survey of 126 paediatricians and family practitioners revealed that 18% of providers did not make appointments with parents for the next immunization, 43% did not call parents to reschedule missed immunization appointments, and 55% did not notify parents of due or overdue immunizations. Interestingly, in a recent study using reminder/recall as a primary intervention, Stille, Christison-Lagay, Bernstein and Dworkin (2001) reported no benefit of reminder in increasing overall immunization rates for the primary series.

Media Influence

The media also plays a key role in messaging about immunization. Gellin, Maibach, and Marcuse (2000) found that 18% of respondents obtained immunization information from newspapers or magazines. Shawn and Gold (1987) reported the significant influence that the Canadian media played in immunization decision-making. There are an array of media outlets such as newspapers, magazines, and television, and more recently, the Internet has emerged as a vehicle for information dissemination.

The media and other sources of public information have also been identified as playing a significant role in vaccine risk perception. White and Thomson (1995) found a connection between media coverage of vaccine issues

and parents' perception of the safety of vaccines. Mothers who had little experience with the impact of vaccine-preventable diseases were more concerned with the safety of vaccines, due in part, as White and Thomson argue, to the "one-sided attention paid by the media to vaccine damage" (p. 79). White and Thomson contend that although serious side effects directly related to immunization are extremely rare and difficult to prove, the media have highlighted alleged consequences resulting from various vaccines. It is clear that the media are effective in delivering immunization messaging, but studies which have explored specifically the experience of parents and the role of the media in immunization uptake were not found in the literature.

Educational Strategies

Several studies point out that educational strategies are important to address the issue of poor immunization uptake. Prislín and colleagues (1998) concluded that low immunization rates among African Americans could be improved through educational campaigns. Conversely, Strobino, Hughart and Guyer (1999) contend that failure of the primary care system, rather than education, has inhibited early and timely immunization services for children. Educational strategies are frequently cited in the literature as an important component of any attempt to increase immunization uptake. However, studies examining educational strategies in relation to the experience of parents as reported by parents were not found in the literature.

Professional Advice to Parents

Some research has demonstrated that the comprehensiveness and value of the professional advice that health care providers give to parents is questionable. Tarrant and Gregory (2001) found that although participants were provided with vaccine information, mothers admitted they had limited knowledge of how immunizations worked or what diseases they covered. The most common reason given by parents for delayed immunization was that their provider recommended delay (Bjornson, Scheifele, & LaJeunesse, 1997). Blair and colleagues (1985) and Klein, Morgan, and Wansbrough-Jones (1989) also found that a decision to immunize did not significantly correlate with previous consultation with a health care professional. Klein and colleagues concluded that there are serious deficiencies in explaining and promoting immunization on the part of health care professionals. In the study by Klein and colleagues of the reasons given by parents for failure to immunize their children, 96% of the parents received advice from a health care professional before deciding about their child's vaccination, and 72% of those parents reported not vaccinating their children due to inappropriate advice or parental conviction not refuted by health care professionals.

Studies have also examined whether parents have a preference for the type of professional who provides the information. In a study by Gellin and colleagues (2000), the majority of respondents (84.2%) indicated their source of immunization information was a doctor and smaller percentages were either a nurse (8.2%) or providers in a health clinic (7.5%). The majority of respondents

(65.8%) indicated no preference for receiving information from a doctor or a nurse. Alternatively, Koepke, Vogel, and Kohrt (2001) found that immunization rates were significantly higher when paediatricians gave advice compared to family practitioners. These results showed that provider specialty was a significant predictor of immunization coverage.

Lay Advice to Parents

The advice received by parents from lay people such as friends or relatives has been identified as a possible factor influencing immunization decision-making. There is little research in this area with the exception of Tarrant and Gregory's (2001) study that found parents received considerable negative advice from their parents and grandparents about immunization. In this study of two first-nations communities, participants stated that elders in the community did not believe in immunizations and did not understand why children had to have so many needles. The elders, unlike the parents interviewed, would have witnessed many of the vaccine-preventable diseases that are rare today. The elders' advice does not acknowledge the reduction in communicable disease due to immunization, but according to Tarrant and Gregory, reflects their distrust of the health care system. The cultural context of this study limits the applicability of the findings to other cultural groups due to the dynamic of elders in First Nations communities. No other studies were found in the research literature pertaining to lay advice, a factor which could potentially contribute to the parental decision-making experience.

In summary, the cues to action discussed in this literature review have the potential to be guiding forces in parental immunization decisions. Unfortunately, very little study has been done to explore these cues to action. The extent to which reminder/recall notices, media messaging, educational strategies and lay advice influence parents' immunization action is unknown. Studies show that parents think reminder/recall is important, but the actual effectiveness of reminder/recall or parents impressions and experience of reminder/recall have not been explored. There has been a considerable amount of study in the area of professional advice and impact on immunization uptake, in contrast to other areas of study. However, similar to all areas of study is the lack of exploration of the parental experience of receiving professional advice and how parents integrate that advice into their immunization decisions.

Demographic and Socio-Psychological Variables

Little research was found examining the relationship between demographic and socio-psychological variables and immunization default, but a few studies have touched on specific areas including parental attitudes, social support, and educational levels. Using a descriptive correlational design, Rosenblum and colleagues (1981) investigated the health attitudes and behaviours of mothers of preschool children. No difference was found in the attitudes and behaviours between immunizing and non-immunizing subjects in the demographic variables studied (age, education, religion, ethnicity and income).

Two studies considered the role of parental attitudes on immunization status, reporting findings which were distinctly different. Prislín and colleagues (1998) found that children's immunization rates were primarily influenced by parental beliefs and attitudes. In contrast, Strobino, Keane, Holt, Hughart and Guyer (1996) reported that children's immunization levels were not explained by the knowledge and attitudes of parents, but rather, by socio-demographic characteristics such as ethnicity, income, and use of social programs. These findings were taken from a study of 735 children in the poorest census tracts of Baltimore, limiting the applicability of findings to the general population. Nevertheless, Strobino and colleagues concluded that "the health beliefs of mothers appear to be far less important than socio-demographic factors such as social support in determining immunization status" (p. 1081), a finding consistent with that of Bates, Fitzgerald, Dittus and Wolinsky (1994).

Social support was identified as another important factor in immunization uptake. In the Bates et al. (1994) study, co-residence with a grandmother was found to positively affect receipt of immunization. Markland and Durand (1976) and Strobino and colleagues (1996) reported that the social support variable presents a compelling picture of children at risk; children living in larger families and in households in which their biological mother was absent had lower immunization rates. Maternal isolation and having no support system were also identified as risk factors by Strobino and colleagues as well as by Sharland, Atkinson, Maguire and Begg (1997).

The education level of parents, both formal preparation and immunization knowledge, has also been explored as a variable in immunization uptake. In the Markland and Durand (1976) study, parents of inadequately immunized children had a lower education level. Better educated parents were less concerned about the safety of vaccines and less distrustful of medical professionals, resulting in a stronger sense of control and, consequently, in higher immunization rates among their children (Prislin et al., 1998). In contrast, White and Thomson (1995) found that the more widely educated and widely read the parents were, the more likely they were to experience a dilemma regarding whether or not to immunize.

In summary, these studies provide important information about the impact of attitudes, social support, educational level and other demographic and socio-psychological variables on immunization uptake. However, no studies were found that explicitly addressed how these variables might influence parent's experiences.

Parenting and Valuing of Parental Expertise

A review of the literature on parenting, parental decision-making in relation to their child's health, and health care provider/parent relationships was conducted. This literature was briefly reviewed to determine how it might inform the present study.

Parenting

The title of a text by Kegan (1994), *In over our heads*, foreshadows the discussion of the challenges of parenting and the contention that many people who are parents may not be up to the task. Parenting theory relates to

immunization decision-making by the simple fact that making an immunization decision is a task of parenthood. Kegan discussed many of the tasks of parenthood including, 1) that a parent has a duty to protect the child, and 2) a parent makes decisions in the child's best interests. For some parents, making an immunization decision may present a dilemma as the individual attempts to fulfil the tasks of parenting. This duty of the parent may be threatened in the case of immunization decision-making. As noted previously, a dilemma may present itself when parents are faced with choosing to immunize in the context of protecting, in a climate of anti-immunization messages and possibly the underlying dynamics of heuristics as discussed earlier.

A parent is expected to make decisions in the child's best interests. A new parent may assume that everyone, including themselves and health care providers, would naturally have their child's best interests in mind when discussing immunizations. Some parents may maintain this view and accept immunization as being in the best interest of the child's health. Thorne (1993) reports that parents may initially trust, believing, that health care providers always hold their child's best interest as paramount. Balling and McCubbin (2001) state that "mistrust can arise when parents learn through experience that mistakes happen and decisions were made that the parents deemed inappropriate" (p. 111). Dixon (1996) suggests that gathering information is a strategy parents use to control anxiety and manage uncertainty. In the context of immunization knowledge, parents exploring the vaccine literature may perceive immunization data regarding possible side effects as potential mistakes, and

thereby, in attempting to protect their child's best interest, may begin information gathering.

Balling and McCubbin (2001) report that some of the information that parents gather may temporarily assuage their fears and form the basis for communication with health care professionals. Angst and Deatrick (1996) made an interesting point about decision-making, stating that the parent must first view the decision as a decision. In the context of immunization decision-making, it is possible that if a parent does not perceive that there is a decision to make for or against immunization, then immunization may occur without discussion. In the Angst and Deatrick study of parental and child involvement in health care decisions in a child with chronic illness, families who saw alternatives did not make decisions quickly. Unlike parents making decisions about surgical interventions, the result of an immunization decision may not be known for an extended period and, therefore, the dynamic may increase the dilemma for some parents. Only in exploring the immunization experience will this knowledge gap begin to be addressed.

Decision-Making in Children's Health

Although the level of decision-making for a child with a chronic illness may be more intense and long-term than immunization decision-making, exploration of the parental experience in children's health in general was anticipated to be informative for this study. Jerrett (1994), in a study of parents of chronically ill children, observed their decision-making in relation to treatment decisions and found that parent's developed expertise in their child's illness management.

Jerrett identified four stages in the experience of coming to know the child's care including, turmoil and confusion, struggling to know, a different way of knowing, and taking charge. It is possible that these types of stages may be similarly found in the experience of a parent making an immunization decision. The initial response of turmoil and emotional confusion was a reaction to feeling unable to cope with what was happening to their child. The second stage of struggling to know was described as being expected to take on an unfamiliar role. The third stage of a different way of knowing, refers to once the parent's have a plan of care, their efforts are directed at a new understanding. Finally, taking charge refers to the perspective of valuing the complexities of care they now understand. "The parents listened to and valued the expertise of the professionals, but also felt that they themselves had their own expertise based on what they had lived through" (Jerrett, p. 1054).

Gibson (1995) studied the process of empowerment in mothers of chronically ill children. Gibson reported that in spite of the challenges that chronic childhood illness presents, many families are able to adapt to their situation and develop a sense of control over their lives. The process of empowerment is observed by Gibson to have four components: discovering reality, critical reflection, taking charge, and holding on. Discovering reality was described as the initial emotional, cognitive and behavioural responses. Emotional responses included realization something was wrong, shock, confusion and fear. Cognitive responses were the quest for information, whereas behavioural responses were doing everything possible for their child. A predominant theme in discovering

reality was frustration, which led to critical reflection, in which the mothers evaluated themselves and their situation. Take charge of a situation occurred once mothers were aware of their strengths and were confident in their knowledge of their child. Although the experience of parents making immunization decisions remains unexplored, it is possible that an empowerment similar to that experienced by mothers of chronically ill children may be part of the experience of parents in their decision-making about immunization.

In general, studies indicate that parents of children with chronic diseases have a familiarity with the health care system and a heightened knowledge of the child's illness. This creates confidence in other areas which relate to the child. This confidence translates into expectations regarding opportunities to ask questions and have questions answered. According to Angst and Deatrick (1996), parental involvement in care-giving and decision-making occurs gradually as parents acquire increased knowledge and comfort and skills. Jerrett (1994) notes that parents eventually develop expertise in their child's illness management. Balling and McCubbin (2001) reported that parents expect that their expertise will be valued and participation in their child's care accepted. A study of the experience of parents choosing not to immunize could fill a knowledge gap of whether they develop a sense of expertise and whether they experience their expertise as valued. As well, a study of the experience of parents who have made a decision not to immunize may demonstrate empowerment similar to that reported by Gibson (1995) or perhaps stages in their decision-making such as those reported by Jerrett.

Health Care Provider/Parent Relationships

A growing number of investigators have studied parents' experiences of caring for a chronically ill child and the health care provider/parent relationships. Dixon (1996) reviewed sixteen journal articles and book chapters to identify the processes by which parents of chronically ill children manage health care relationships. Dixon organized her findings under four broad concepts: trust, information gathering, participation in care, and decision-making. Dixon reported that "decision-making between parents and professionals changed over time, as the parents' competence and knowledge grew" (p. 123). Dixon identified four patterns of decision-making: Professional Dominated, Participatory, Challenging, and Collaborative. Professional dominated decision-making was evident initially when parents were feeling overwhelmed or in shock and the "decision-making was one-way, from professional to parent" (Dixon, p. 123). In participatory decision-making, parents usually agreed with professionals' decisions but began to recognize their own participation as important. Challenging decision-making showed a shift in the balance of power from the health care professional to the parent. Collaborative decision-making referred to "taking charge" (Dixon, p. 125) as parents gained expertise and approached professionals as equals. Thorne (1993) reported that parents were able to achieve a "reconstructed trust" (p. 93) in which they were able to rebuild a trusting relationship without the naiveté that was present in the Professional Dominated decision-making pattern.

Although I found no literature specifically regarding immunization decision-making of parents with chronically ill children, researchers examining parental

involvement in their children's health care decisions have noted that many parents desire involvement and this involvement is strongly related to their satisfaction with care (Angst & Deatruck, 1996). This involvement may be potentially threatened because professionals may be reluctant to involve parents in the decision-making process, and thus, the process may be difficult for some parents.

When asked what they want from health care providers in the decision-making process, parents wanted to be given honest and complete information, to work with health care providers who recognized the human impact of decisions, to be consulted in planning and decision-making, and to be viewed as credible and valuable (Angst & Deatruck, p. 179).

The impact of the parental experience of being included or not included as a decision maker with the health care provider may help to understand the impact on immunization decisions.

Leahey and Harper-Jaques (1996) presented five family-nurse relationships that may help to understand health care provider and parent relationships related to decisions for immunization. Leahey and Harper-Jaques state that "the current trend in health care is away from the hierarchical view of provider domination" (p. 136) and that "in a non-hierarchical relationship, each person's contribution is acknowledged and valued" (p. 137). Benner (1984) recognized and popularized the concept of nurses developing expertise in clinical practice and Leahey and Harper-Jaques make a connection with families who manage chronic conditions developing expertise. They report that "often there

are clashes between the needs of health care consumers and the services delivered by health care providers” (Leahey & Harper-Jaques, p. 140). The current perspective is away from health provider as expert toward fostering the provider/parent or patient relationship and valuing the parental/patient expertise. Thorne and Robinson (1988) state that “health care professionals cannot afford to promote naïve trust In addition we in the health care professions must work towards identifying and understanding the discrepancies between the perspectives of our patients and ourselves” (p. 788). This information may be important in helping to understand the relationship between parents and health care providers as parents make immunization decisions and health care providers interact with parents. It is possible that clashes or discrepancies may exist between the needs or expectations of parents as health care consumers and the services provided by or perspectives of the health care providers related to immunization decisions.

Summary

Factors which influence decision-making have been studied and some information exists related to immunization uptake and the potential role that demographic and socio-psychological variables play in immunization decision-making. At the same time, there is a surprising lack of knowledge related to how parents describe their experience of immunization decision-making. No studies were found which asked parents to describe their experience of choosing not to immunize their child and whether any of the factors thought to influence immunization decision-making were part of their experience. Further, although

cues to action were identified in the literature as potentially significant guiding forces in parental immunization decisions, little is known about the actual experience of parents receiving cues to action and how parents would describe that experience in relation to their immunization decisions. It is also unclear how parents feel in their interactions with health care providers and others when they make a decision not to immunize their child. Given that many of today's parents may be faced with both strong societal pressures and pressures from health care providers to choose immunization, it seems that an understanding of the experiences of parents who make a decision not to immunize their child is warranted. Therefore, this qualitative study aims to provide a detailed contextual description of parents' experiences when they decide not to immunize their children.

Research Question

A small number of studies have begun to explore parental experiences, attitudes, beliefs and behaviours, but few conclusions have been clearly articulated. Many questions related to parents' experiences with immunization decision making remain unanswered or have never been posed. Many aspects of immunization uptake have been tackled by research studies, but most of the conclusions do not take into consideration the importance of the parents' perception. To begin to address the interrelated nature of experience and decision-making, a broad question guided this study. The research question which guided this qualitative study was: How do parents who have decided not to immunize their children describe their experience of that decision and interpret

the reactions of health care professionals and others to the decision?

Definition of Terms

Parent – father, mother, or legal guardian of a child who has the legal right to make decisions regarding health care service receipt for that child.

Child – a minor individual who has not reached the age of legal right to consent to health care services.

Others – refers to extended family members, friends, neighbours, acquaintances, or anyone else that a parent may discuss an immunization decision with.

Chapter 3

Methods

The purpose of this study was to gain insight into the experience of parents who have made a decision not to immunize their child. Research has the potential to provide insight which can be instrumental in assisting health care provider intervention. Although many aspects of immunization and decision-making have been explored, few studies have considered parents' experiences with making a decision not to immunize their child. This study builds on the existing body of knowledge in order to provide a more complete picture of the experiences of parents.

Research Design

An interpretive descriptive design was used for this study. Interpretive description "is grounded in an interpretive orientation that acknowledges the constructed and contextual nature of much of the health-illness experience, yet also allows for shared realities" (Thorne, Kirkham & MacDonald-Emes, 1997, p. 172). Interpretive description should be put in context with existing knowledge so that what is known, either by formal research or clinical interpretation, becomes foundational to a new study (Thorne et al.). An analytic framework based on critical analysis of existing knowledge is suggested as an appropriate platform to build a qualitative design (Thorne et al.). Because the framework is a starting point rather than an organizing structure for the findings of an inquiry, it is expected that the framework will be challenged as the inductive analysis progresses (Thorne et al.).

An interpretive description that is meant to generate nursing practice knowledge is recommended to have purposeful selection of research participants whose descriptions of their experience reveal components that are to some degree shared by others (Thorne et al., 1997). Not all data will reflect a common experience, but “an effective interpretive description will be one that distinguishes eccentricities from commonalities within its process and outcome” (Thorne et al., p. 174). The authors of this methodology believe that an understanding of how people experience their health and illness can be created by sound interpretive description and provide direction for nursing to make a difference (Thorne et al.).

Interpretive description methodology fit well with exploration of the experience of parents who choose not to immunize their children. Interviews were conducted with each participant to explore their experience of choosing not to immunize, including the experience of their interpretations of health care provider response and the response of others to the decision.

Participants

Participant Recruitment

Nine parents were recruited. The sample was recruited in a couple of key ways. First, the Public Health Information System (PHIS) child health immunization record was accessed via audit by prevention services staff and provided to the audit public health nurse. Names and contact information of parents who had stated that they did not plan to immunize their child and who agreed to be contacted for research purposes were identified by the audit public

health nurse during the usual audit process¹⁰. I provided information letters about the study to the audit public health nurse. The audit public health nurse sent the information letter and invitation to participate (Appendix A) to the parents instructing them to contact me directly if they were interested in participating in the study. All parents who had declined immunization and who expressed an interest in the study were sent an information letter. Four parents contacted me indicating their interest in participating. These participants requested letters of invitation for friends and colleagues who they felt also fulfilled the research criteria for participation. I provided letters of invitation to participants who requested them, following their interview. Those letters were hand delivered by participants to friends and colleagues, accompanied by a brief explanation of the project. This recruitment resulted in a further five participants for a total of nine participants in the study.

The type of sample used for this study was purposeful as recommended for an interpretive descriptive design. According to Morse (1991), "requesting that people with the desired experiences contact the researcher, increases the types of participants and therefore broadens the potential range of experiences available to the researcher "(p. 131). I attempted to ensure that all sides of the experience under study were represented by recruiting participants with different experiences. I achieved this by screening all potential participants. When a potential participant contacted me, eligibility and inclusion in the sample was

10 Usual Audit Process involves the production of Public Health Information System audit reports at ages 4, 6, 8, 14, 24 and 26 months of those children who are not up-to-date for immunization according to their age. The parent is contacted by the Audit Public Health Nurse to determine the circumstances for the delay, at which point a parent who is opting not to immunize will be identified.

determined in the telephone contact. The initial contact also included screening participants about their experience in order to determine that they were willing and able to describe their experience, and determine the general nature of their experience. As the study progressed, potential participants with atypical or different experiences were sought in order to have as representative of a sample as possible. For example, during a screening contact, one of my participants stated that she had an older child with autism which she believed to be vaccine related and therefore her story was anticipated to be atypical.

The qualitative principal of appropriateness was met by selecting informants best able to meet the informational needs of the study (Morse, 1991). Interviews were arranged with participants who were deemed to be good research participants by virtue of their articulate, thoughtful, and eagerness to share their experiences and analyses of their situation (Thorne et al., 1997, p. 174). The researcher determined these qualities by asking potential participants during the screening contact to briefly describe their experience.

Inclusion/Exclusion Criteria

Parents who had declined immunization for their children were recruited to participate. All participants were over 19 years of age, spoke English, and resided in the geographical catchment area served by the Vancouver Island Health Authority – South Island. Parents who were delaying immunization and planned to immunize at a later date were not included in the study. Those individuals who did not fulfill the selection criteria or who were unable to give fully informed consent were excluded from this study. For example, one potential

participant who had begun immunization and chose to discontinue was excluded from this study because she stated her preference was to immunize but allergies precluded that choice. Another potential participant explained that she was not interested in participating in the study but felt pressured by her husband (a University Professor) to participate because he felt supporting graduate students was important. This potential participant was excluded from the study after we discussed the possible implications of participating in a research study when feeling pressured to do so.

Description of the Sample

The sample consisted of eight mothers and one father. Throughout the study, I sought participants who represented a range of experiences (e.g. parents who had both positive and negative experiences) and whose children varied in age. The variation in the children's age was felt to be important in order to explore the experience of parents at various ages and immunization milestones of their children. I collected demographic data on all participants (Appendix B). Participant demographics included age, gender, level of education, and the age of the child/children. The parents ranged in age from 25 to 45 years, with a total of 17 children ranging in age from 4 ½ months to 12 years. The parents' level of educational preparation ranged from less than high school to advanced University degrees. Five parents had one or more university degrees, one parent had a college diploma, two parents graduated high school and one parent did not complete high school. Included in the sample were seven stay-at-home mothers (two of whom were home schooling their children; one who had a child with

autism), a chiropractor, and a homeopathic practitioner.

Data Collection Procedure

Data were collected by unstructured interviews that lasted approximately one to one and a half hours in length. An interview guide (Appendix C) was used for all interviews and one interview was conducted with each participant. I audio-taped and transcribed the interviews myself. Interviews were arranged with the parents at a time and location that was convenient to them, with as few distractions as possible. I used an interview room at the Vancouver Island Health Authority Research Centre when it was convenient for the parent. This room was used as the location for interviews in the majority of cases. Most parents expressed that they were not comfortable having the interview conducted in their home due to the demands of young children. In addition, public spaces tended to be too noisy for audio-taping. Therefore, the interview room provided an environment very conducive to the interview and the audiotape. The location of the Research Centre was central and all the participants who came there found it convenient because of bus routes.

The interviews in this study were formal in that they were prearranged with informants for the purpose of detailed conversation rather than being chance encounters. The interviews were done in face-to-face encounters with one informant at a time. The interviews were unstructured, "defined as those that do not reflect preconceived ideas about content or flow and are done with little or no organization" (May, 1991, p. 191). Although the term 'unstructured interview' may imply that the investigator is conducting the interview without prior information,

experience or opinions of the topic of study, it actually refers to the goal of discovering and understanding the informant's perspective (May) without the structure of the interview being determined by the interviewer. I exerted only as much topic guidance as was necessary during the interview to elicit the participant's story (May). As a novice interviewer, it took two or three interviews to relax the guidance being provided during the interviews. During the early interviews I tended to stick very closely to my interview guide. However, after those initial two or three interviews, I began to relax my interview style, starting the interview with a broad question such as, "if you could just tell me about how you came to make the decision not to immunize?" As the study proceeded, the interviews became slightly more focused "to test preliminary findings, or begin to look for areas of commonality and difference in respondent's stories" (May, p. 192).

As an unskilled investigator I was aware that the dynamic of framing questions in language rooted in my previous nursing knowledge without being aware of this could possibly occur. Repeated review of interview audiotapes and transcripts was used to assist in detecting the presence of this dynamic. I transcribed the interviews and produced them in both electronic and hard copy format. The interview data was organized by assigning a number to each interview and creating files in Microsoft Word to correspond with the identity number. I also used a journal to record observations or insights about the interview and these were recorded immediately following each interview. This process of reflection helped me to critically reflect on my comfort level in the

interview process and how the flexibility and fluidity allowed in the later interviews enhanced participants comfort and freedom to share their experiences.

Data Analysis

The data was analyzed using inductive analysis. Thorne and colleagues (1997) suggest “struggling to apprehend the overall picture with questions such as ‘what is happening here?’ and ‘what am I learning about this?’ as these types of questions will typically stimulate more coherent analytic frameworks for interpretive description” (p. 174). Thorne and colleagues recommend analytic techniques that involve repeatedly immersing oneself in the data before beginning coding, classifying or identifying linkages. Deductive analysis, for example, predetermined analytic strategies, such as content analysis, or small units of analysis such as words or phrases, was avoided. Premature coding, which may result in superficial understandings at the expense of deep and meaningful analytic interpretations, was also avoided. Data obtained in interviews with parents was transcribed and read and reread in order to immerse myself in the data prior to beginning to attempt to create linkages. As Morse and Field (1995) state, “theory does not emerge from data without immersion in and complete familiarity with the data and without active intellectual work” (p.125).

Thorne and colleagues (1997) also state strategic periods of immersion in the field interspersed with periods of immersion in the data “seem ideally suited to research endeavors that require refining the enquiry, testing the developing conceptualizations, and challenging the abstractions that emerge with strategic theoretical sampling” (p. 175). Immersion in the field could be interpreted as data

collection periods, which in this study, were participant interviews. In this study, data was read and reread from the first interview and then another interview was conducted and the same process was used of immersion in the data, thereby interspersing field and data periods.

Thorne and colleagues (1997) suggest that the analytic procedures capitalize on such processes as synthesizing, theorizing and re-contextualizing, outlined by Morse (1994), rather than simply sorting and coding. Synthesizing refers to the merging of several stories or experiences to describe a typical, composite pattern. Synthesizing is also described as the sifting part of the analysis, or weeding the significant from the insignificant (Morse). Theorizing, according to Morse (1994), may be "considered as the sorting phase of the analysis" (p. 33). The process of analysis cannot be rushed. Therefore, theorizing requires a process of systematic selection of alternative explanations and comparing with the data, to find the best and most simple explanation for the data. Re-contextualization is the development of emerging theory so that the theory is applicable to other settings.

As Sandelowski (1995b) suggests, I read each interview as many times as was necessary to grasp its essential features, without feeling pressured to move forward in the analytic process. Interpretive description in nursing requires that nurse researchers come to know individual cases intimately, abstract relevant common themes from individual cases, and thereby produce knowledge from the collective that will itself be applied back to individual cases (Thorne et al., 1997).

Morse (1991) states that “managing variation descriptively can be accomplished by using thick description to explain a concept” (p. 139). I sought to describe the experiences as richly and accurately as possible by carefully and fully describing all possible perspectives or types of experiences revealed. This in turn ensures that the analysis is not skewed toward one perspective (Morse) Thick description was accomplished by using direct quotations from the data, in order to provide as rich and accurate an account as possible.

Rigor

Rigor in research “is required to prevent error of either a constant or intermittent nature” (Morse & Field, 1995, p.143). Initially, qualitative research was criticized as lacking in control of validity and reliability of the findings. Researchers have attempted to address these issues. For example, Lincoln and Guba (1985) described four criteria for ensuring validity and reliability of qualitative research. Specifically, four aspects of trustworthiness are believed to be important in qualitative study: truth value or credibility, applicability, consistency, and neutrality or confirmability.

Truth value or credibility “is subject oriented and not defined in advance by the researcher” (Morse & Field, 1995, p. 143). Morse and Field contend that in qualitative research, one recognizes multiple realities, so the researcher’s job becomes one of reporting the perspectives of the informants as clearly as possible. Checking credibility may involve reviewing the findings and interpretations with the participants. Thorne et al. (1997) state that built into the design of an interpretive description is repeated interviewing, in which developing

conceptualizations can be subjected to challenges or refinements as the study progresses. In order to review the findings and interpretations with participants, as the study was ongoing, interviews were structured and timed so that confirmation of the findings and interpretations were sought after every two or three interviews with the next group of informants.

Applicability is the criterion used to determine whether the findings can be applied in other contexts. Applicability can be achieved by coming to know individual cases intimately and, thereby, producing rich descriptions of the findings. In this study, I have attempted to use 'thick description' to illustrate parents' perspectives. However, I am aware that the findings are based on interviews with a small sample from one geographical area and that the applicability or generalizability to other situations or contexts may be limited by this.

Consistency is used to evaluate trustworthiness. Qualitative research emphasizes the uniqueness of the human situation so that variation in experience rather than identical repetition is to be expected (Morse & Field, 1995). Consistency in the documentation of the process to ensure that the findings are supported by the data is critical for the conclusions to be trustworthy. Accuracy in transcription and consistency in interview technique, as well as immersion in the data creates confidence in the findings of this study.

Neutrality or confirmability refers to another criterion used to establish rigor which provides freedom from bias in the research procedure and results (Morse & Field, 1995). Clearly identifying not only the process of the inquiry but

also biases of the researcher is essential in adhering to rigor in a qualitative study. In my professional position as a public health nurse working in communicable disease control, the expectation exists that I express a positive attitude about vaccines and immunization. Therefore, I was aware of my possibility for bias in relation to immunization decision-making. I am also frequently called upon to discuss with parents the risks and benefits of immunization in a non-judgmental and supportive manner. I believe I have been effective in discussing parents' concerns in a positive manner, and therefore, depended upon that experience while conducting participant interviews. Morse (1994) states, "the investigator must act like a sponge, absorbing and drawing in information, maintaining a spirit of inquisitiveness, rather than a judgmental or evaluative manner" (p. 28). I maintained awareness of the possibility of bias during interviews and, while reviewing the audiotape and transcribed data, watched for signs of bias in the formulation of questions or language used.

Thorne et al. (1997) state that a reflective journal is a valuable asset for many researchers to guide as well as document "the reactive processes of interpreting or countering bias within the research process" (p. 175). To ensure that the analysis was grounded in the data, a reflective journal was used to record observations and findings, identify my biases, as well as record the development of my analytic reasoning process.

I was concerned about my position as a public health nurse and whether participants would feel comfortable and safe in sharing their experiences. I found that only two of the nine participants expressed concern initially and once I was

able to distinguish the study from my employment, participants expressed relief. During the interviews, other participants required some reassurance that I wanted them to be as open and honest as possible even about interactions with public health nurses.

Prior to the beginning of the interviews I was not sure if I would experience frustration or judgment in hearing about the reasons parents might give for not immunizing. I recognized that in being well versed in the evidence used to refute those kinds of arguments, I might experience frustration or judgments. In actual fact I found myself captivated by these parents' stories. I felt sad and frustrated at times when hearing how they were treated by health care providers and others. I felt empathy for their struggles and the feelings that they shared so openly. I did not anticipate for one moment that these parents would not have been treated with respect and provided with a standard of care unaffected by a decision not to immunize. Thus, I found my journal reflections expressed intense disappointment at times. During the interviews I did not try to explain the actions of members of the health care community, but rather, I responded with genuine interest and empathy to their stories and in some cases, their pain.

Ethics and Human Rights Considerations

Researchers using human subjects must ensure protection of the human rights of study participants and the study must be conducted in an ethical manner. In this study, ethical and human rights considerations include informed consent and confidentiality. Prior to conducting the study, approval was obtained from the University of British Columbia Behavioural Research Ethics Board and

the Vancouver Island Health Authority Research Ethics Review Committee.

Permission was granted by the Manager of Prevention Services to access the PHIS audit public health nurse as a contact for information about possible study participants.

Informed Consent

All of the potential participants received a letter outlining the purpose of the study and the nature of their participation prior to them deciding to participate (Appendix A). The researcher's name and contact number and the name and contact number of the thesis supervisor were included in the introductory letter. Potential participants who wished to further discuss the possibility of participating were asked to call the researcher directly. Participants were told that participation in the study was voluntary and would not impact in any way on the services they access from the health care system. The participants were assured that their participation was anonymous and that they had the right to withdraw and refuse to answer any questions at anytime. Participants were asked to sign a consent form (Appendix D). The consent form outlined the number of interviews and the approximate length of time needed for the interview and that the interviews would be tape recorded and transcribed.

Confidentiality

Anonymity and confidentiality were maintained throughout the study. The names of the participants do not appear on interview data and any reference in the interview content which could potentially identify an individual was deleted or altered. Each interview was coded with a number and only I had access to the

cross-reference list of participants names. Demographic information was collected using a demographic form (Appendix B) and was stored separately from the data to ensure names of participants are not linked to the data. Transcripts and audiotapes are kept in a locked cabinet. Transcripts were only available to myself and my thesis committee members. I transcribed all of my own transcripts. Any published findings will not include any identifying information of the participants involved.

Limitations of the Study

Although I have much experience talking with parents about making decisions for and against immunization, this research may be limited by my inexperience as a principal investigator. Sample size is another concern in relation to qualitative study design limitations. Sandelowski states:

An adequate sample size in qualitative research is one that permits by virtue of not being too large the deep, case-oriented analysis that is a hallmark of all qualitative inquiry, and that results in by virtue of not being too small a new and richly textured understanding of experience (1995a, p. 183).

A sample size of 9 informants allowed a rich description of the experience without being so large that the opportunity for analysis was overwhelming. Nevertheless, I do recognize that the sample size is small and limits the generalizability of the findings.

Potential Significance of the Study

Many research studies have considered the impact of a parent's decision not to immunize on immunization uptake. This study has the potential to provide

insight into parents' experience of a decision not to immunize and how they interpret the reactions of health care professionals and others. This knowledge could inform health care professionals and others' understandings of how their reactions to a parent's decision influence the parent's experience. Knowledge gained from this study may also be used to inform the development of strategies to assist health care professionals and others in their interactions with parents. The study findings may also assist parents who are making immunization decisions to understand the experience other parents have had making such decisions.

Chapter 4

Research Findings

The overall purpose of this study was to gain a better understanding of the experiences of parents who make a decision not to immunize their children. Data analysis of the interview transcripts of the nine parents in this study revealed many commonalities and some differences in the parents' experiences. Three main themes emerged from the data, including, (a) seeking to be informed, (b) seeking to be supported, and (c) seeking to have their decision accepted.

The first theme describes the experience of parents as they seek to become informed about immunization, by searching for information and seeking the advice of experts such as health care providers. The second theme describes the experience of parents as they seek to be supported while making an immunization decision and having made a decision not to immunize. Parents described the decision and their experiences of receiving support and having had interactions ranging from respectful to adversarial. In addition, parents described strategies they utilized to cope with their experience. The final theme describes the experience of parents as they seek to have their decision accepted including parents' questioning of the decision, parent's taking responsibility for the decision, and finally, their perception of care and access to services.

Seeking to be Informed

Many of the participants described a desire to be well informed about immunizations prior to making a decision for or against immunization. The parents' decision was not made quickly or lightly, but rather, with care and

concern for the welfare of their child. Most of the participants began to consider immunization as a decision *"before birth, long before birth,"* and some began considering immunization long before they ever intended to have children. There were several factors that influenced the decision and many of the participants engaged in active strategies to enable informed decision making including, searching for information, seeking expert advice, and making judgments about the credibility of information and advice.

Searching for Information

Parents reported varied reasons for the initiation of their interest in immunization decisions. The majority of parents seemed to be interested in seeking out information on immunization as a result of impending parenthood. The topic arose in a variety of ways. As one parent described, *"it sort of just kept coming up, in conversations with other parents and some of the literature that I was reading."* Most often these parents reported that they were reading parenting literature when the topic came to the forefront. A few parents also researched the topic before even contemplating becoming parents. One parent, referring to her training as a homeopathic practitioner, stated that her interest in the topic came largely through her education. Similarly, another parent took up an interest in immunization for professional and academic reasons when studying to be a chiropractor. Another parent explored the question of immunization because she was interested in alternative health. For these parents, searching for information in order to be well informed was not a new experience.

All of the parents reported that they had read literature and some had done research on the internet and attended lectures on the issue of vaccine and immunizations prior to making a decision regarding immunization. One participant stated, *"I did a lot of reading and I researched it ... I feel like there's a certain group of parents who wouldn't question it, wouldn't read about it. I felt like I did that."* Another parent reported doing *"a lot of research, like books and whatever I could find."* All of the participants reported reading books and popular literature, such as Mothering magazine. Some parents also read medical journals. One participant, referring to herself and her physician-husband stated, *"we do try to look at whatever research there is out there, both for and against, and we're always reading whatever medical journals come."* This participant also reported that her husband attended scientific conferences to learn more about immunization and was impressed by the different researchers that spoke at the conference. Other participants had success researching on the internet as a source of vaccine and immunization information. Internet sites such as the Vaccine Risk Awareness Network and personal websites of individuals who were involved in vaccine issues were also commonly accessed. One participant, in referring to an internet search stated that she, *"got lots of very valid information ... that confirmed her belief that vaccinating a baby is not a good idea."* The participants' research took various forms. However, in general, all of the participants seemed to be very well read on the subject of vaccine and immunizations.

Although the reasons for initiating and conducting research, and the sources used related to immunization varied for these parents, it was a common link through all of the interview data that these parents made the decision only after attempting to become well informed on the subject. Accessing information and the neutrality of the information they sought and found were commonly identified by parents as factors in the success of their search.

Accessing Information.

While it is clear that parents attempted to avail themselves of as much information as possible, they identified access to available information and the freedom to seek information as limited. Some parents identified instances in which they were satisfied with the information they were able to obtain from health care professionals and others. One parent recalled a conversation with her physician-naturopath stating that, *"there was a sense of relief, you know, being able to get correct information, not just hearsay, not just opinions."* Parents sought information from sources which they valued and whose information was perceived to be correct. For example, websites, articles and books written by physicians, chiropractors and other health care professionals were perceived to be valuable if the individual was perceived to be "an expert" by virtue of having written or spoken extensively about immunization. Parents seemed to determine correctness based on whether or not they understood the arguments and whether the information supported their understanding of the issues.

Many of the parents, however, were frustrated by the difficulties they perceived in accessing information. One parent who had attempted to discuss

immunization with her physician and a public health nurse inferred conflict and difficulty while seeking to be well informed when she stated:

We weren't getting answers about things ... I guess I wish that it wasn't such an intensive war, either you do it [immunize] or you don't do it. Because I think that intensity is really robbing parents of the ability to get a clear answer.

The difficulty in gaining information was, at times, experienced between partners, as one wife described:

To vaccinate and not vaccinate, there's no middle ground. We [my husband and I] had a few tense moments, but it was sort of wearing him [husband] down, because I just would ask the same things over, repetitiously. What about this and what about that? So I guess he realized after a while I wasn't trying to get him to defend his opinion. I was looking for more information to support a decision that I had to come to.

Some parents also felt that immunization information that was not consistent with the recommended standard of care was withheld from the public in order to control outcome. This created tension and dissatisfaction for some parents and left them feeling that the "system" could not always be trusted:

The system [referring to the medical establishment] has some investment in having everyone doing exactly the same thing. That's my feeling. That's about all systems isn't it? But, I think the system withholds information in order to facilitate cooperation.

Other parents suggested the business sector was also responsible for withholding information about immunization. As one parent suggested, *"the whole truth wasn't being told by the medical community, but also by the drug companies."*

Some of the parents identified reluctance or a lack of freedom to ask questions while seeking information, and, in some cases, fear of negative consequences. One participant in particular described her concern of being judged about her parenting decisions and as a result, was reluctant to express her concerns about immunization:

I remember getting a call from one of the nurses from the CRD ... I didn't know if I was honest about my concerns about vaccination how I would be perceived ... If I question it are they going to get upset?

Other parents expressed a lack of ease while trying to interact with physicians, suggesting that they felt uncomfortable questioning medical practitioners and feeling, in turn, that physicians were not open to discussions about immunization as this parent suggested:

I just feel like there's so much hysteria around all of it, that there aren't clear answers about what each vaccination does. So I was trying to ask her [physician] that, and I felt like that wasn't okay to be asking for one thing, because it was seen as confrontational, like I didn't trust her knowledge or her ability or whatever.

The parent's own prior treatment experiences with health care professionals also seemed to influence whether they felt free to ask questions

about their children's immunization, and sometimes, parents felt that professionals were not always open to being questioned. One parent, who had attended an immunization clinic, recalled an experience of being given an injection while attempting to ask questions and clarify her desire to proceed with the injection. This situation left this parent feeling reluctant to ask health care providers questions about immunization:

I was working in the field and I remember going to get a Hep B vaccination, even at the last minute saying, "I don't know about this, I hear it's not good for you, or that you can sometimes have bad reactions" ... And she [the nurse], I think was feeling annoyed about, what are you doing questioning at this last minute? You're here for your appointment to get it. And right in the middle of me going, well blah, blah, blah, jab right in the arm.

It is possible that parents applied previous experiences of seeking information they had with health care providers to seeking immunization information and that these experiences led them to anticipate difficulty. As the previous interview segment implied, previous experiences with health care providers made some parents feel that they could not question. Another parent described her frustration in seeking information from public health in the context of a well-baby clinic. She reported, *"any concerns I had I didn't find were addressed."* Some parents expressed frustration that the information that they were seeking was not available to them even though they were able to identify specific concerns. For example, one parent identified having difficulty finding out what was *"really in vaccinations, [and] how to track vaccinations if your child has*

a response.”

In trying to access information related to immunization, many parents found that there was *“no middle ground.”* That is, immunization was either fully supported as a necessary health intervention or was viewed as a health risk, and therefore, not supported. As one parent explained, *“the research ... was fairly limited because very quickly it appeared that there were really two camps, that there was pro-vaccination and anti-vaccination.”* Another parent reported that the *“non-vaccinating camp”* has a *“liberal attitude”* whereas the *“pro-vaccination camp”* ascribe to a *“medical model.”* Parents felt that although *“both camps want what’s best for their children, what is needed is information that presents the facts on both sides.”* Some parents described that *“each [camp] was intense and political and very much had its own agenda.”* It was this intensity and political nature that disturbed many of the parents in the study, because, had this not been the case, these parents felt that information would probably have been more easily accessed.

Neutrality of Information.

Many of the parents expressed a desire for information that was *“neutral, rather than one-sided.”* Several of the parents suggested that the information obtained from health care providers tended to lean toward pro-immunization. Parents sought neutral information, where both the pros and cons of immunization were discussed. However, as one parent explained, getting health care practitioners to understand her immunization decision would have been most helpful as would have getting unbiased or neutral information:

I'd like to have a doctor for all kinds of things, but somebody who will understand about some of the decisions that I've made and give me information that isn't biased or what they think is right.

Many of the parents reported that the information that they were able to access, whether it was in the literature or from health care providers and others, was most often biased toward immunization. One parent reported that she *"could not find any information that was unbiased,"* a discovery commonly reported by participants. Parents cited that pharmaceutical company involvement in literature available to parents put the validity and neutrality of the information into question. As well, literature written by individuals who were recognized as being against immunization put the value of the anti-vaccination literature in question. One parent explained:

The information that is pro-vaccination is often funded by the drug companies and the information that is anti-vaccination is often written by people who have an agenda before they even start.

The lack of neutrality in information being offered to parents by health care providers, in the context of obtaining immunization consent, was also raised as a concern by some parents. These parents reported that the information that was given to them to obtain consent was pro-immunization and did not address any of the issues of vaccine safety or possible long-term consequences. Parents concluded that without unbiased information, informed consent was difficult. One parent who had initially intended to immunize her child reported that she changed her mind because she was not being given neutral information:

Consent that parents are giving who are immunizing is not informed consent because they are being given very little information, and what little they are being given is biased.

This mother reported that she could not find any research studies looking at the effects of vaccination and disease which were un-biased. She suggested that the authors were already biased either pro or anti-vaccination.

As parents sought to become informed about this controversial and, at times, emotional issue, they found themselves having to sift through opposing views - a task, according to study participants, made more difficult by the resistance of health care providers to discuss the topic openly or to give consideration to the evidence on both sides.

Questioning the Establishment.

Perhaps due to the lack of opportunity for discussion, parents found themselves defending their position and expressing a mistrust of big business and the "*medical establishment*." Parents expressed concern about the relationship between doctors and pharmaceutical companies, and the perception that the relationship cast suspicion on physicians' motives in recommending pharmaceutical products, including vaccines. One parent reported, "*Doctors get a lot of perks from prescribing certain drugs from drug companies.... It's not just straight forward, let's help the people. There's big business. So that makes me a little suspicious.*" Similarly, another parent expressed mistrust of the reasoning for vaccine to be only available as polyvalent vaccine preparations. This mother may have considered immunization with single component vaccines if they were

available. She stated:

What about all these, MMR¹¹, three things at once, when do you ever get sick with three things at once? And I think that's just the medical system can't be bothered to, this is my opinion, to separate it out.

One participant described her perception of the impact that big business had on health decision-making. This parent believed that chickenpox vaccine was developed and promoted because employers were incurring large costs when parents stayed home with ill children. The availability of vaccine for a common childhood disease like chickenpox potentially reduced employee absence. She stated:

The chickenpox vaccine is because somebody sat down and said it's costing us so many billion dollars a year because parents are staying at home with their sick children. So let's get the chickenpox vaccine out there.

Another parent described her perception of the relationship between pharmaceutical companies and hospital funding, and her perception of the impact if hospitals stopped promoting immunization. This parent believed that the hospitals were dependent upon pharmaceutical company funding, implying that the nature of that dependent relationship impacted on hospital messaging to parents, such as hospitals encouraging immunization. However, she implied that if hospitals did not promote pharmaceutical products such as vaccine then hospital funding would be put in jeopardy. She stated:

What about funding that we get for our hospitals from the pharmaceutical companies? What are they going to say? It gets so deep and so

11 MMR is short form for Measles Mumps Rubella vaccine

complicated. I know this stuff is going on you guys, so don't tell me that, that all this is going on for my own good.

Several parents expressed suspicion of big business as evident in the preceding examples. The suspicions expressed by parents seemed to originate from the perspective that the manufacturer of a product is not a neutral voice in presenting the attributes of that product. In addition, making profits from health care seemed to be viewed negatively. In the case of vaccine, parents perceived that the value of vaccine was potentially overstated and perhaps misrepresented since the body providing the information was profiting from a positive public perception of the product.

The "*medical establishment*" was also questioned by parents. All of the parents had a perception that "*the establishment*" or some authority influenced their experience of making an immunization decision. One parent expressed mistrust that the medical association was not willing to examine the alternatives to immunization or the controversial facts about immunization. She implied that the medical establishment had not taken the time to examine the immunization issue, in part, because of fear that the immunization program may be put in question. Most of the parents expressed concern that they not be perceived as being anti-establishment, since they did not feel and would not identify themselves as such. Although these parents found themselves questioning some of societies *norms*, they stated that questioning of a specific practice was important to them and not simply anti-establishment. One parent differed from the others when she implied that she found herself, throughout her life,

questioning any authority or practice in which society expected conformation. She reported that when she initially became interested in the question of immunization decisions *“at some point it sort of became medical establishment and just a process of questioning any authority that was assumed that we were just to follow unquestioningly.”*

Parents recognized that not immunizing was such a politically charged issue with certain health care provider groups that some health care providers did not want to discuss their opinions of immunization for fear of being identified as anti-vaccination. One participant reported a conversation in which her midwife declined to discuss immunization:

I could tell she felt it was a political topic and she felt that it's hard enough being a midwife right now. She doesn't want to bring any other things into that. She doesn't necessarily want midwives being linked with no vaccinations. She didn't want that. You could tell. And then, opinions that individual midwives have shouldn't reflect upon the College of Midwives.

Parent's perception of health care providers seemed to be one of guarded trust. The health care provider was seen as someone who had a job to do, but also had a larger organizational structure to answer to. For example, one parent questioned a public health nurse's motivation, implying that the nurse was protecting herself rather than being concerned about the parent:

Is this nurse really concerned about vaccination, or is she concerned that if she doesn't bug me enough and finally get me to vaccinate that her boss is going to be mad at her?

Similarly, some parents believed that information was being withheld for political reasons. One participant surmised that, *"generally, I think parents, are only told what is the party line about immunization. They are not told everything."*

Some parents seemed to feel that not only were health care providers not free to share openly, but they were also not allowed to question immunization. As one parent stated, *"I think that's a problem for nurses and docs to not be allowed to question.... There may be political reasons for the College to say something like that."* The perception that governing structures prevented health care providers the freedom to question and provide an honest appraisal of their findings tended to take the focus off individual health care providers and place it on the respective Colleges. Parents then, were understanding of health care providers' positions and were less frustrated with individual health care providers.

Most of these parents undertook a difficult task in questioning immunization. The difficulties that parents had in accessing immunization information made it difficult for them to approach their decisions feeling that they were well informed. In addition, parents found that the information available to them was neither neutral nor provided the facts about immunization in a clear and comprehensive manner. As a result, parents seemed to mistrust big business and the medical establishment and this seemed to further hamper their access to information.

Desire for "Expert" Advice

Many of the parents sought *expert* advice as a way to become informed about immunization decisions. While seeking expert advice, particularly from

health care providers, many parents found themselves questioning the credibility of providers and the information that they offered. Parents also recognized the political nature of immunization decision making and the “pressures” that health care providers may be under to adopt a pro-immunization stance.

Credibility of Health Care Providers and Their Advice.

As mentioned earlier, some of the parents felt inhibited to question health care providers about immunization. As many of these parents had done a substantial amount of research to inform their decisions, they had accumulated a comprehensive knowledge base and it seemed that they were well prepared to assess the *expert advice* of health care providers. Some parents expressed a positive regard for health care providers who they perceived to have the desired knowledge and who were open to being questioned. The openness of health care providers made these parents feel comfortable and confident that the information received was credible. These parents appreciated the in-depth knowledge of these health care providers as one parent stated:

I think there's that sense of comfort for me, going to MDs who practice alternative medicine, because I see that they have the depth of knowledge that I need and they also are willing to explore.

Many of these parents did not seem to accept a health care providers' advice simply on the basis of assumed knowledge as a medical professional. As one parent explained *“I remember talking to my doctor.... I think she was shocked that I was asking questions, and not just assuming that she knew best.”*

Many of the parents were looking for health care providers who had a depth of knowledge about immunizations. More often than not, however, these parents found that health care providers did not have a knowledge base that met their standards. One participant stated, when referring to her physician, that she *"found him sadly lacking in information about vaccination."* Some parents judged a health care providers' credibility based on their own knowledge of a specific disease process. For example, one parent, who had done extensive reading about pertussis¹² when her child was ill questioned her physician when the physician suggested that her other two children could not become ill with whooping cough because they had been immunized -- a fact the parent knew was incorrect. This experience led this mother to question the physician's credibility.

Other parents judged a health care providers' credibility based on their openness to consider information that the parents had obtained in their research. When a participant was asked if he had shared his immunization information with his physician, he reported that his physician *"was not willing to listen to it."* In this situation the health care providers' perceived resistance to listening to the parent's information negated the value of the physician's information for this parent. The parent, in referring to his physician, stated:

If you're not going to listen and he [family physician] wasn't willing to do that ... That blinds the whole issue. So, we're going with the information I have, because I got the information from sources that I trust.

¹² Pertussis is the bacterial organism which causes pertussis illness or more commonly referred to as whooping cough.

Some parents perceived that individual physicians may push immunization because they do not have time in their busy daily routine to address immunization questions. One parent was not willing to have a physician push immunization because taking time to discuss her concerns was inconvenient. As she described:

They're [physicians] not willing to look at the alternatives or the controversial facts about what it is they do because it's just too much work ... And I know this and again I think you're just another person. You are [physician] just another person who knows a lot more about this [immunization] than I do, but you have your daily grind that you have to deal with. And I know that. So I'm not going to let you, push your daily grind on me [be]cause the establishment hasn't taken the time to take a closer look at this [immunization]. Because they're too afraid, because what if it [immunization program] all falls apart?

Some parents also suggested that their mistrust of physicians' and nurses' recommendations to immunize arose from their belief that these health professionals did not approach the subject with critical thought. Rather, these parents implied that some health professionals' opinions resulted from indoctrination. As one parent stated:

I don't feel that it's [immunization] discussed as a choice or with a lot of critical thought - like there's a possibility that maybe vaccinations aren't as great as everybody thinks. That there's controversy, and that it's worthwhile to consider the controversy. I don't get that sense. I get a sense that it's

really like indoctrinated, like it's a one-way street.

In addition, some of the parents reported that they wished health care providers would also question immunization and read literature that was both pro and anti-vaccination. These parents felt that if health care providers could address parents' concerns from an informed perspective rather than only promoting immunization, parents would have more confidence in the health care providers' opinion. One parent stated that she doesn't *"think people see a lot of questioning by people that are administering these treatments [immunizations],"* and, therefore, *"that leads to lack of credibility."*

Some parents asked health care providers pointed questions in order to test the health care provider's knowledge and to determine the credibility of their advice. For example, one parent questioned a public health nurses' knowledge to find out how much the nurse knew about the vaccines that were being given. In this instance, the parent was surprised by the nurse's lack of knowledge:

I asked the public health nurse about the concentrations, and how does the dosage vary when they're young to when they get older ... She didn't have any answers ... She didn't have a lot of information about vaccinations and what they were and what were in each of them.

The credibility of information sources used by health care providers was also questioned as a way to determine the credibility of health care providers' advice. One participant reported that health professionals commonly made statements to support immunization and indicated that there was no research to

link certain vaccines to specific diseases or outcomes (e.g. autism¹³). This parent disagreed with health professionals making claims about lack of evidence when she believed that there was no evidence because research had not been conducted:

Sometimes people [parents] are told there's no evidence that this [vaccine] does this [outcome]. Well it's because there is no research that's been done. And those statements get bandied around. Then, people don't realize well they can say it because they've never done the research, not because they've done the research and it's shown this, it's because there's no research.

The credibility of internet sources used by health care providers was questioned by parents as well and some parents reported that health care providers questioned their use of internet sites that were not *sanctioned* by the health care provider. One participant recalled an interaction with her physician in which she was told that the internet information she had obtained was not credible. In this interaction, however, the physician then advised her to use the internet as a source of information leaving this parent confused about how to proceed:

Ironically ... some of the information was websites, and I thought, Oh isn't that ironic, like it went full circle. At the beginning she was sort of suggesting that any information you get from the internet is misleading and doesn't have

13 Autism is a complex developmental disability that typically appears during the first three years of life. The result of a neurological disorder that affects the functioning of the brain, autism and its associated behaviors have been estimated to occur in as many as 2 to 6 in 1,000 individuals (Autism Society of America, 2004).

any real basis in truth, credibility. And yet, in the end, she was suggesting that I find some answers I was looking for on the internet.

Maintaining the Status Quo.

Some of the participants commented on the political nature of immunization decisions and their beliefs on how it influenced health care providers and their willingness to share expert advice openly and honestly. Some parents suggested that health care providers were in a difficult position because they must follow the status quo, that is, pro-immunization. These parents suggested that having to maintain the *"status quo"* left some health care providers uncomfortable with discussing immunization choices. Some parents believed that a health care provider who entertained the idea or supported parents in not immunizing their children could be disciplined by their governance body. One parent reported that, *"it appears that it's not okay for anyone in the ranks to question [immunization]. If they do they get slapped down."* In fact, one parent reported being told by her physician that she had to maintain the status quo. This participant recalled a conversation with her physician where the physician stated, *"I have to tell you that you should vaccinate.... I have to tow the party line."* In this instance, the parent said that the physician was referring to the College of Physicians and Surgeons, a governance body that supports immunization and prescribes physician responsibility as it relates to immunization.

Other parents reported that health care providers were not comfortable discussing immunization choices because of peer pressure. When parents

referred specifically to physicians, one mother stated, *"They are criticized by their peers if they question it [immunization]. They suffer if they question things."*

Parents acknowledged that they were influenced by the political nature of immunization decisions. For example, even if physicians and nurses were to discuss immunization openly, parents were left to sort out the messages in a climate perceived to be less than transparent. Parents found it difficult to determine whether a physician's pro-immunization stance was genuine or simply an attempt to maintain the status quo. As one parent described, *"If parents perceive that doctors and nurses are not allowed to question then it also makes their spiel less believable."*

Parents also found themselves being challenged to maintain the status quo, not only by physicians and other health care providers, but also by family and friends. Some parents reported interactions with family members that they perceived to be emotional and upsetting and where family members were very clear that immunization should be done *without questioning*. As one parent reportedly was told, *"there isn't really a decision to be made. It's what you do, when you have kids, you follow the routine of the schedule, and that's what happens."*

These parents found themselves in a difficult situation. They wanted to avail themselves of the expert advice of health care providers and yet, the political nature of the issue put the truth or value of the advice in question. Parents were left feeling disappointed that they were unable to access the level of expert advice that they felt was reasonable to expect. Some parents felt a

need to defend the research that they had done in making their decision. One parent stated, *"You know, we're not neglecting them [their children] by making this choice. This is something we've thought about and we've researched."*

Making a Decision Not to Immunize.

While most of the parents found the immunization decision to be a difficult one, some parents did not have difficulty at all. One mother had begun her research on the topic many years before the birth of her children and had made similar decisions for alternative approaches to health care. Therefore, she seemed more confident of the decision from the outset than most of the other parents. Another parent seemed confident because she and her husband were prepared to manage any illnesses that may occur and they were not concerned about that possibility: *"My husband is a physician and has done the same reading that I have done and we both felt pretty confident in our decision."* On the other hand, many of the parents described how difficult the immunization decision was to make. As one mother reported, she was not *"happy with having to make the decision,"* and *"agonized over the decision often late into the night."* While many parents had gone through the effort of becoming as informed as possible, they reported that *"it's easier just to believe the experts."* The experience of making the choice about immunization seemed to be uniquely difficult, so much so that some parents found themselves *"prolonging it [the decision] because they couldn't even really make a firm decision."* It seemed that some parents began the decision making on the premise that they would not immunize unless they found adequate information to convince them otherwise.

One parent reported that she did not feel well informed, and therefore she *"just felt like [immunizing] was one step [she] didn't want to take."*

Other parents described the decision as a dilemma because on one hand, they were afraid that their children would contract communicable diseases, but on the other hand, had learned through their research that immunization could cause autism or that continuous vaccinations over the long term could affect a person's immune system. As has already been suggested, parents found themselves having to choose between two options: immunization which they perceived could cause harm immediately or as a long-term consequence, and disease, which they perceived could have similar effects. As one parent described, *"I didn't really like either of my options. I felt that was the big thing for me in making a decision. What was the lesser of the two not nice things?"*

In the end, parents were often left to make the decision by weighing the information they could find which usually consisted of conflicting choices and opinions. Some parents who initially described the decision as difficult expressed confidence as they made their choice. One parent stated, *"I think I became more confident and I started to realize that I could make decisions that weren't necessarily what everybody else was choosing to do."* Other parents, although they made a decision not to immunize and were confident that it was the right decision for them, still described themselves as *"taking a walk on the wild side,"* and *"swimming upstream."*

Seeking to be Supported

Just as parents recognized the need to be well informed about immunization, support seemed to be an important part of the experience of making an immunization decision. These parents chose to make a difficult and sometimes socially unacceptable decision, with one parent commenting that *"it's easier just to do what everybody else does."* As another parent reflected, *"society feels that there isn't really a decision to be made. It's what you do, when you have kids."* Parents looked to health care providers and others not only for *expert advice*, but for support as well. Sometimes parents received respectful support from health care providers and others, in the form of affirmation and acceptance. At other times, their interactions were perceived as lacking in support, sometimes to the point of being adversarial.

All of the parents described the importance of support when making immunization decisions. For example, one parent reported that *"It's important that there be support out there. It seems like it's either one way or the other. There isn't a lot that's sort of saying I know it's hard either way."* Parents also expressed a desire for support in the form of acknowledgement of how difficult it was to make an immunization decision. One parent implied her desire for support and stated her disappointment when she reported that, *"nobody has ever said to us, once, that's a hard decision to make."*

Other parents described the struggle to make a decision about immunization as a dilemma and expressed their desire for acknowledgement of the dilemma. For example, one parent described an interaction with her

physician and said she felt frustrated that her physician was not willing to acknowledge the dilemma she was facing. Another parent described her desire for acknowledgement that she had made her decision with the best of intentions and not with disregard for her child's well-being. She stated:

It would have gone so much further I think for her [family physician] to have said, or anyone to say, "when I see your kids I see they're healthy, I see they're happy, I see that you're doing a really great job, you obviously put a lot of effort into what you're doing and you care about it, and so it only follows that your choice is made with that same intention, that same integrity." ... Just acknowledging that the parents or that I have the best intentions.

All of the parents described, the desire for support and the importance they placed on receiving support while making the decision about immunization for their child. But, few of the parents could recount such experiences of support. Parents described experiences of being supported and not supported from both health care providers and family members.

Feeling Supported

Many of the parents appreciated being supported in their decisions. For instance, parents felt supported by health care providers when they felt the health care provider was knowledgeable about, questioned, and had personal experience with immunization. Even when health professionals did not share the parents' perspective on immunization, parents still felt supported as long as the health professional was able to see the parents' point of view and were open to

their decisions. Parents were appreciative when health professionals were open and did not follow the *"status quo."* One participant described an interaction with a public health nurse when she needed support for her decision. The mother reported, *"this person [nurse] was great. She was just willing to listen to me.... She didn't agree or disagree."* Having support from health care providers who were open to discussion and questions, while allowing parents to make the decision, seemed to be an important factor in facilitating parental satisfaction, although that experience was not common among the participants.

Many parents appreciated encounters with health care providers in which they felt respected. For example, some parents described interactions with physicians where the physician was *"willing to let me make the choice."* This same parent appreciated when her physician was *"straight forward with what he thought,"* implying that parents welcomed honest and truthful information, regardless of whether the health care provider agreed with their decision.

One participant appreciated being *"left alone"* with her decision and described her experience as positive: *"On the whole it's been quite positive, Positive as in not negative, okay? As in not, oh, you really ought to! I think I've been more or less actually left alone, so that's been okay."* Only one parent described her experience as fully positive. However, she indicated that this was because she did not seek information or advice from health care professionals.

Some parents said that they did not mind being questioned about their decisions but suggested that the motivation behind the questioning influenced how they reacted and felt about the interaction. In addition, whether or not the

questioning was done in a respectful manner seemed to impact the perception of support. For instance, one parent explained that she felt supported by her nurse practitioner and was okay with the nurse practitioner questioning her about whether her son was still un-immunized because she felt that the nurse was *"just asking for confirmation.... I think she's just [asking] because she's doing her job."* Another parent felt okay about being questioned by her friend because the questions asked were raised out of concern and interest:

I have a girlfriend. Her response was, "Oh, really, do you think that's safe to do?" And she's a little more cautious. She's highly educated and is very, like wanted all the facts. She wanted to know why [I had made the decision].

This type of non-confrontational questioning seemed to be acceptable to parents.

Some parents thought that others would try and impose their opinions, but even when this happened, these parents said that was acceptable to them as long as the opinions or questions were shared in a respectful manner. Many parents expressed a desire to receive information, but wanted to have the information delivered to them in a respectful way as this parent stated: *"Give me more information. That's what I want. Give me, please give me more, and please do it respectfully. Please don't treat me like I'm stupid or neglectful or not diligent as a mother."*

Only a few parents reported experiences of feeling supported by family and friends. In describing the support of friends, one parent reported that her *"... friends have been supportive, because our circle of friends is pretty alternative ... I support you in your decision and you support me, because we both understand*

that this is controversial." It was the exception for participants to describe acceptance from family, however one participant did report *"I think my parents just sort of accepted my decision just assuming I had worked it out or done the research."*

A few parents reported experiencing support which could be termed conditional support because its presence depended upon a certain condition existing. One parent reported that she and her husband experienced support because they had suggested to hospital staff, during their son's hospitalization, that they were still contemplating immunization. She recalled, *"If we ever suggested that we weren't sure, we were kind of contemplating vaccination, a lot of support to vaccinate.... It felt really good to have some support."* Another participant reported that she received support from a public health nurse until she shared her decision not to immunize. This parent perceived that the public health nurse was interested in talking to her as long as there was a chance she would immunize. In recalling a postnatal telephone assessment by the public health nurse, she stated:

We talked for a while and it seemed to me that all of a sudden when we got to the immunization thing ... and I said I don't think I'm going to immunize her. I'm not sure but I don't think I will. And it just seemed like very suddenly the conversation wrapped up.

In both of these situations the parents' perception was that as long as they were thinking about immunizing they received support. In essence, support depended upon the parent adhering to the norm, or seeming to be thinking about

maintaining the status quo.

Feeling Unsupported

Parents reported interactions with health care providers, family and friends in which they did not feel supported. Lack of support was also described as disrespect in the form of bullying, judgment, hostility, emotional arguments and adversarial statements. One parent who had taken her son for a consultation with a pediatrician about a concern unrelated to vaccine-preventable disease found herself being “*lectured*” by the physician about not having immunized her son. She was confident about her decision and found the physician’s attitude to be disrespectful since she was not asking him for input about immunization and she was not interested in listening to a lecture. In the context of a general medical history the mother reported:

I think he asked me whether he was vaccinated, and I said “No.” I knew I was in for a lecture then as soon as he asked me. I think I just sort of shut down. Because I knew I was in for the lecture. My mind was made up. I had done a lot of research. [I was] not really listening to what he was saying.

Some parents reported not feeling respected when health care providers did not accept their decision even when they indicated it was firm. One parent recalled that her physician asked her repeatedly at every office visit whether or not she would immunize. This repeated questioning annoyed her as she stated, “*After about time fifteen, it was a little annoying.*” Another participant reported a similar experience of being asked repetitively about his decision stating that, “*the public health [nurse] kept calling here almost once a week and it actually drove*

us a little bananas."

Participants reported attempting to discuss their research with health care providers and use it as an opportunity to ask questions. Some parents felt disrespected in these instances. One parent summarized her experience with a physician. She stated, *"I just felt like I was getting the dumb mother treatment."* Parents expected that they would be able to ask questions and engage health care providers in conversation. Instead, they found themselves being spoken to in a *"disrespectful tone"* and having their concerns or sources of information dismissed. These interactions seemed to prevent these parents from not only feeling respected but from getting the expert advice that they desired.

Several parents reported that they experienced incidents of shaming when being questioned about immunization. Parents experienced instances in which they perceived health care providers to use public forums to shame parents about their immunization decision. One parent reported that she attended her daughter's kindergarten orientation and a public health nurse stated, *"Well the majority ... of children ... a very high percentage of children in this school are immunized, which is very good for those of you who have chosen not to immunize."* The participant's perception was, *"that little jab about how they're better parents than we are and we're riding on the backs of all those people who have subjected their children and taken the risk of vaccination."*

Judgment was also experienced by parents making the decision not to immunize, from overt statements to covert or less obvious messages. One parent stated that she experienced judging *"not necessarily from one group in particular*

but I would say pretty pervasive across the board ... from the most subtle implication to a real overt [statement]." Parents reported that although most people did not tell them directly *"I think what you're doing is wrong,"* there were a number of ways that parents experienced judgment, including from health care professionals. One participant who described a visit to the Emergency room in which she felt that the judgment was expressed in tone and awkward silence, stated, *"there was definitely a tone of [judgment] when they said, 'So when were his vaccinations?' ... We had to say, 'well he hasn't been vaccinated yet.' And it was like, hmmm!"* She described, *"a pause, it was like a very quiet yet potent pause."*

Parents reported interactions with health care providers which felt adversarial without being overt. This tended to make communication awkward and getting useful information difficult. One participant recalled receiving a phone call from a public health nurse that left her with the feeling that *"you're one of those people ... Like it was us against them"* whereas other parents recounted overtly adversarial encounters which prevented any productive communication between parent and health care provider. In these instances parents seemed to feel discouraged and, in some cases, accosted. A parent was asked by her family doctor in an *"overtly hostile"* manner, *"So why aren't you vaccinating?"* Another parent recalled a conversation with his physician that left him feeling frustrated:

[The doctor said] "You're not going to immunize?" I said, "That's right." He said, "Oh I really think you should." I said, "No that's fine I'm not going to."

He said, "Well I don't understand! Where are you getting your information from?" I said, "That's OK, I'm well versed in it." He said, "Well is it internet information?"

Parents also reported that health care providers used strategies in an attempt to sway their decisions and this sometimes resulted in emotionally charged arguments. However, when arguments occurred, this made it difficult for parents to listen to what health care providers had to say: *"[it was] hard to really hear any of the positives, the content, or even some of the truths or the messages that maybe were worthwhile hearing, [because] it was like so over the top [when the doctor was lecturing me]."* Some parents said that health care providers used "scare tactics" and that this made the parents discount any valid arguments the health care provider may have made. One participant described an emotional argument during a consultation with a pediatrician and explained that, *"The whole consult consisted of him giving me hell for not vaccinating my children ... He says he saw kids dying ... That I ought to. That it's terrible. That he's seen children dying from these diseases."* This parent felt patronized and frustrated as she did *"not get the information [she] came for."* Another participant described the response of her former family doctor to her decision not to immunize her children. She described that the doctor's response made her feel *"horrible ... accosted in a way ... like punished or chastised."* She explained:

I was actually quite appalled by her [physician] response because I really felt like it was very intense, and very emotional and very sensationalized ... and really getting emotional about vaccinations, and saying things to me like

“well I’ve seen a child’s brain turn to mush.”

One parent described a telephone call from a public health nurse in which she felt attacked and unable to respond, leaving her with a sense of frustration and powerlessness in light of the seriousness of the statement. She reported that the public health nurse was quite hostile and stated *“this is second to child abuse you know, when you don’t vaccinate your children.”* Similarly, another parent reported that during a visit that her child had to the Emergency department a nurse *“. . . was really frustrated. She did not hide her frustration.”* She asked, *“Are your immunizations up-to-date?”* And then after a long emotional argument, the nurse stated, *“The reason we vaccinate children is so that they don’t bring it home to the babies,”* leaving the parent feeling *“. . . sad, defenseless and slightly neglectful.”*

Parents also described interactions with health care providers (unrelated to an immunization decision) that they felt were negatively impacted by having made the decision not to immunize. One parent reported that when her daughter was ill with whooping cough, she felt that *“. . . body language, facial expressions as well as the general approach to me and my daughter all indicated a lack of support due to the fact that she was not immunized.”* It seemed that the lack of support for the decision was applied generally to other situations as a form of stigmatization.

It was common for participants to report negative reactions and lack of support from family to their decision. One parent reported an adversarial response from her mother who was questioning her decision: *“It was intense ...*

we had a huge, bad fight about it, an argument." Another parent reported feeling shunned, stating that her parents were *"not supportive at all"* and, in fact, they requested that she *"not tell their friends or visit when their friends were over"* for fear the subject of immunization would come up and their friends would find out that she was not immunizing. One participant, in describing the lack of support of her family, said that she was hurt by how her parents felt as illustrated in the following interview segment:

Not support from family. You don't really mind a stranger not giving you support, and it may give you a bad feeling for ten minutes and then you drive off and it's over. But [not] having your family ... that really hurts, because you want at least your close friends and your family to be able to support you and to listen to what you are saying.

One participant described a paternal grandparent's¹⁴ bullying behavior in which the parents were left feeling that they would not be able to leave their child alone with the grandmother. This parent recalled, *"When she came down and she found out that we'd decided not to vaccinate, she said 'well I'll take him to the doctor myself.'*" Another parent tried to discuss her choice with her mother and present some of the research which she described as *"equally compelling, suggesting what kids are getting from vaccinations."* She reported that it *"doesn't go over too well"* and suggested her mother resorted to emotional arguments, leaving her feeling hurt and unsupported.

Some parents identified grandparents as demonstrating overt judgment by making broad statements which did not leave the parents any opportunity to

¹⁴ Grandparent refers to the grandparent of the child who is not immunized.

respond or discuss their perspective. One participant reported that her husband's mother said that she and her husband were unfit parents because they did not vaccinate. Another parent referred to her own mother, a nurse, who reportedly stated, "*Parents who don't vaccinate their kids are totally irresponsible.*" This parent further explained that when she had tried to discuss her decision with her mother, her mother claimed, "*Well I've seen a dead child,*" inferring that not immunizing was a bad decision.

Parents also reported instances of bullying from other parents which left them feeling isolated and at times attacked, as in the following interaction which reportedly occurred at a public health Mother's group. The participant stated that:

There were probably about twenty Moms there, and they seemed like they were all pro-vaccination. The public health nurse was there and I was asking her questions and so it was obvious that I was skeptical about vaccinations. And so it almost felt like a lynching, you know, because some of them turned around and looked at me and said, "You'll never be able to take your child to daycare, and you'll never be able to leave them anywhere.... If anything goes wrong, you will just die a thousand deaths."

Several of the parents repeatedly described feeling unsupported. The instances they reported took various forms, but in general, the parents were left feeling discouraged and cautious. As a result of their insights and experiences some parents began to develop strategies to aid them in coping with unsupportive interactions in order to help them in meeting their own needs.

Strategies for Supportive Interactions

In instances where parents felt disrespected or unsupported in discussing their immunization decisions, some parents developed strategies to help defuse the tension they experienced such as showing respect and an openness to the other's point of view (usually a health care provider). As one participant said, *"I think that's the key. When you're doing something that is controversial, try to show respect for other people's concerns and anxieties."* This participant further explained that showing respect for another could provide benefit to her. In an interaction this parent had with an emergency nurse she suggested: *"If I go in there and I show respect for them [staff], maybe they'll back off a bit and understand that I'm not a loony toon from the back woods."* She further went on to explain how she dealt with a public health nurse who was reportedly *"belligerent."* She expected that the public health nurse would act professionally and treat her with respect. However, when that did not happen, she was still willing to try to view the situation from the public health nurse's perspective and cut her *some slack*:

I expected better from her [the nurse]. But, I also tried to respect her frustration, that from her point of view, I'm a nutter. And so why wouldn't she get frustrated with me? And I'm willing to give her some slack. Again, a person trying to do her job.

Some parents described using confrontation as a strategy for interaction. Some parents felt like they were perceived as being confrontational just by virtue of the nature of the topic. At other times, parents felt that in order to be heard or

taken seriously they sometimes found themselves being confrontational. One parent, who was called several times by a public health nurse, recounted the following experience:

The public health nurse called me three times about getting [her younger daughter] vaccinated. [The nurse asked], "Why are you not vaccinating?"

The third time she called me I said, "Okay, I will vaccinate her, the only thing you have to do is, I'm going to make a form in which you are to agree personally that if my daughter becomes autistic, you are personally going to help me throughout my life to care for this child." [the nurse said] "Oh No, No, okay." So I was never phoned again.

Because some of the parents felt that they had to justify their decisions repeatedly, and because they felt that their decision was under constant scrutiny, some parents adopted a code of silence about their decision. Specifically, some parents avoided telling others about their decision or were dishonest when asked about it. Avoidance was a common strategy used by many parents. For example, when one mother received a phone call from a public health nurse to discuss immunization, she avoided sharing her decision by telling the public health nurse that she and her husband had not really made a decision, when they actually had. In further describing this interaction, the mother implied that her avoidance stemmed from not knowing how to communicate their decision and not wanting to suffer the repercussions as a result:

I said, "Well we haven't really made a decision about that yet." And that was part waffling. You know, just trying to buy time.... I'd rather not deal with

whatever they're [public health] going to have to deal with if I bring it [not immunizing] up. I was clear about what I wanted. I wasn't clear about how to communicate that without stirring up trouble and confusion for myself or basically flak. I was sort of waffling with the nurses.

Avoidance was also used frequently with family and friends. One father reported that he talked to his mother once about the decision and she became angry and emotional. As such, this husband and wife decided to no longer discuss the issue with his mother. Similarly, another participant who experienced emotional arguments from her and her husband's parents found herself avoiding the topic. Otherwise, as she reported, interactions were *"tense"*:

We don't talk about it because people around us, like in our family, especially of an older generation, like of my Mom's age or my husband's Mom's age, they're really passionate about it ... So it either doesn't get talked about or it's really tense.

Another participant took a different approach in avoiding discussions of her immunization decision. When the discussion became uncomfortable she would tell people that she had not yet come to a definite decision and would try and *"change the subject."* In another instance, a parent was dishonest with her brother because she was concerned he would be unhappy with her decision. She told her brother that her daughters were immunized in order to avoid discomfort for herself. As she explained, *"I lied to my brother, I lied ... Because he said, 'Well she's [older daughter] immunized isn't she?' [Parent said] 'Yeah of course she is.' I just didn't want to deal with it."*

Along with avoiding discussions about immunization, some parents adopted a code of silence with friends or others even if they were engaged in conversation about immunization. One parent suggested that unless he was asked directly, he would not share his decision with others because he perceived that others would think that he and his wife were making the wrong decision. Similarly, another participant found that trying to talk with friends who had immunized their children was uncomfortable and, thus, this parent did not feel free to talk openly. As she stated:

We have friends who vaccinate and we have friends who don't vaccinate ...

With the people who have vaccinated we don't really broach the topic ...

Other things where we're making similar choices we'll talk more openly about those things.

Another mother adopted a code of silence and was uncomfortable sharing her decision at her child's school with other parents because she feared their response. She reported:

I think a lot of people are open-minded and a lot of people do consider it to be a decision that you make ... I think I fear the other parents because they're just worried about their own kids. I understand that. I don't think I'd feel comfortable. I have some concerns about sharing that information.

Generally parents reported that they felt *"badly"* about resorting to dishonesty or avoidance in order to deal with health care providers and others about their immunization decision. At the same time, they seemed to feel that their approach was justified by the experience of disrespect that they had

endured including bullying, judgment, hostility, emotional arguments and adversarial statements.

Parents sought to be supported while making a difficult and controversial decision, and when support was found, parents seemed to feel respected. In some instances, however, parents felt that health care providers and others were uncomfortable in addressing their decision, in an open and non-judgmental manner. As a result, parents experienced a range of responses from feeling supported to, at times, feeling attacked and ostracized. Some parents felt they were isolated and their motives were misunderstood. Many parents developed strategies to deal with others' reactions to their decisions and to avoid feeling disrespected as a result of their decision.

Seeking to Have the Decision Accepted

Having made a decision not to immunize their child, parents sought to have their decision accepted by health care providers and others. This final theme will describe how parents found themselves questioning their decision while seeking acceptance and having to learn to live with their decision. In addition, this section will describe the influence of the decision not to immunize, including taking responsibility and the perception of care and accessing services.

Questioning the Decision

It was common for parents to question their own decisions. Several parents reported that they or their partner experienced doubt about their decision at least once, usually in the context of illness or being questioned by others. One parent stated that her husband got scared when their children got whooping

cough and consequently, she found herself questioning whether they were being irresponsible having chosen not to immunize. Another participant who experienced the illness of a child unrelated to vaccine-preventable disease described the doubt that her husband experienced having been asked to justify their decision in the context of a hospitalization. These parents found that the frequency with which they had to state their decision and justify it made them feel increasingly uncomfortable - to the point where her husband wanted relief by going ahead with immunization as she explained:

I saw a real shift in his [husband] thinking about it. But it wasn't like, "okay, I'm changing my mind so now I really want to look into it." It was just like "okay we should just vaccinate. So let's just do it." Like too much, too hard to keep justifying not doing it [immunizing]. Let's just do it and get it over with and we don't have to worry about it.

Another parent, following an emotional argument with a physician, found herself questioning whether or not she was doing what was best for her child:

I felt I was an incompetent Mom. It really made me feel like, I guess I'm not doing a very good job because maybe I'm being selfish about you know, that choice [not to immunize]. Like I'm not really doing what's best for my child. I think that was certainly suggested and I definitely felt that.

Some parents described that they continued to have ambivalent feelings about their decision and about not maintaining the "*status quo*." As one parent stated:

I think that we all as parents feel so unsure of the things we're doing for our

kids. We always want to make [a decision that is] best for them. Whenever we're not doing what everybody else is doing we have these very ambivalent feelings.

Taking Responsibility

Parents described the responsibilities that making a decision not to immunize involved. They described being responsible for making an informed choice after being given sufficient information and support. One parent acknowledged the responsibility of having to make an informed choice after her physician provided support and information. She reported:

He's willing to let me make the choice and take the responsibility too. You know, I've [physician] done my job, I've told you what I think you need to know, and you have the responsibility as a parent to make the correct choice.

Parents also felt responsible for the possible ramifications of their choices. One parent acknowledged that she had made a choice that involved risk and that she shoulders the responsibility of that risk. In referring to her physician-homeopath, she stated "*[He's] helping me I think take responsibility for the choice I made. Yes I'm taking a risk. He doesn't disguise it.*"

Parents experienced fear of having the responsibility for a decision not to immunize and described the fear of trying to defend their decision. One mother described her experience of anticipating discussing her decision with an emergency physician. She reported:

I was a nervous wreck. I felt like a caged animal when he walked out of that

room. I was in those little cubicles with a baby ... and [I'm thinking] okay, what am I going to do? ... What are the facts? ... By the time he comes back I better have a good case.

Parents also described how they feared their child getting a disease as a result of their decision. One mother described her fear following an interaction in which she tried to defend her decision to her family physician. She recalled, *"I was terrified. There was this imminent demise like just waiting around the corner to jump on the kids ... I was just genuinely scared that something bad would happen to them, like they would get really sick."* Although most parents were prepared to take responsibility for their decision or defend the decision when necessary, one parent described being asked the basis for her decision in which she indicated she felt anxious because *"it's real hard to recall all of that information in a moments notice."*

Parents also expressed the need to take responsibility for long-term outcomes, such as opportunities they perceived that may be lost due to their decision. For example, opportunities for children to be involved in activities or programs may be lost, as one mother reported:

I've actually heard people say, you won't be able to put your kid in certain schools if they're not vaccinated ... or they won't get into daycares, or ... if you wanted to enroll them in certain programs, if their not vaccinated, they won't get in.

Parents acknowledged the need to take responsibility for their decision, but also described concerns about their perception of care and access to services that

they encountered along with the responsibility.

Perception of Care and Access to Services

Parents perceived that the immunization decision *"clouds everything"* including perception of care and access to services. Parents reported that once a health care provider knew that the child was not immunized, even if the contact was unrelated, the care they [parent and child] received was influenced negatively by knowledge of the immunization decision. One participant described her perception of the impact on care as a result of a decision not to immunize, such as feeling like public health was no longer a resource for her family. She reported, *"I'm always getting the sense that I'm not getting the best care I can get because I've made that choice."* She further reported:

I believe in public health, just like I believe in public school, and I really want to support that. But by the same token, I'm going to go where I'm actually getting the best outcome, which is kind of too bad because I would like to be getting it from public health. I would like to be able to go to the public health nurse.

Several parents expressed discomfort accessing services and reported an impact on their freedom to ask questions unrelated to immunization, based on their decision not to immunize. This dynamic was described by one parent who stated: *"You're afraid to actually ask for help or ask questions because you know the vaccination question is always in the background."* Parents described how they would access service or information, but at the same time, were concerned about what the experience may be like. One parent, referring to accessing public

health, stated:

I think I'd be worried about the kind of reception I would have, you know, about me saying that I hadn't immunized him [my child] and him being sick ... I'd be worried about that happening. But I think I still would phone and I still would ask and look to them.

Parents described how their discomfort prevented them from accessing service. One parent described that she was anxious about her son possibly being underweight, but avoided seeking assistance based on her decision not to immunize. She reported:

I have never gotten him weighed or measured until just recently, despite the fact that I've had nagging anxiety that he's underweight ... I wouldn't go to community health ... I avoided it, like consciously and subconsciously because I didn't want to go in and deal with the vaccination question. I didn't get his weight ... I just have avoided seeking out conventional medical help or public health.

Similarly, another parent reported an experience with a public health nurse which prevented her from accessing further services. She reported, *"This public health nurse. I was going through a hard time. I needed her. I needed information about what to do ... and I was not willing to call her up again."*

All of the parents expressed or demonstrated an interest in alternative health care. Many of the parents sought alternative health care approaches and the guidance of alternative health care practitioners when they experienced dissatisfaction and frustration with conventional health care. One parent

described her difficulty in trying to get information and support from her physician and public health nurse and how she had finally sought alternative health care. She stated, *"I just have avoided seeking out conventional medical help or public health. I would probably be more inclined to see my homeopath first."* Other parents sought input from alternative health care practitioners because they had previously used alternative approaches for their own or other family members' health care needs. One parent described her introduction to alternative health care stating, *"I went to see him [homeopathic practitioner] because I wanted to boost my daughter's immunity, and I wanted to do it homeopathically."* Another parent stated her reasons for utilizing alternative health care when she simply stated, *"... I'm interested in alternative health."*

Parents reported that they perceived their care and access to service was impacted by their decision not to immunize, even when the care or service they desired were unrelated to immunization.

Summary

The experience of parents in this study points to an unpopular and socially unacceptable decision made in a climate of intolerance. The decision not to immunize produced many experiences for parents. The experience began as parents grappled with the question of immunization, some during pregnancy and others, long before having children. They were influenced by a multitude of factors some of which included information obtained from research and popular literature, opinions of friends and family, anxiety about vaccines, and mistrust of big business. Some parents began their exploration of the topic for educational

purposes such as chiropractic or homeopathy. Others began their exploration as any concerned parent with their child's welfare in mind.

These parents lived in a world in which immunization of children was the norm and they utilized various strategies to make the decision and live with their decision within that context. Parents were challenged by the availability, neutrality, and credibility of information available to them as they worked to become well informed. They acknowledged the strain of the diametrically opposed views of pro-vaccination and anti-vaccination with little middle ground. Some parents felt supported in their decision, but feeling supported was the exception rather than the rule.

As parents began to formulate their decision, they acknowledged that questioning of the decision occurred by themselves and others. Parents reported interactions they experienced during that period which ranged from respectful to adversarial. Parents reported that some health care providers and others used strategies such as bullying and emotional arguments to try and influence their decisions. Parents learned to live with their decision by acknowledging the controversy and disclosing their decision in varying degrees. Some parents were upheld with affirmation while others were faced with hostility, but either way, these parents have learned to navigate access to service whether that was conventional health care or alternative health care.

Chapter 5

Discussion of the Findings

Studies to date have provided knowledge of factors which influence decision making about immunization and the potential role that demographic and socio-psychological variables play in immunization decision making. To my knowledge, no studies have focused explicitly on asking parents to describe their experience of choosing not to immunize their child and how parents feel in their interactions with health care providers and others when they make a decision not to immunize their child. The primary purpose of this study was to describe the experiences of parents who choose not to immunize their children in order to explore avenues which nursing has the potential to influence.

Once parents have made a decision not to immunize, it is unlikely that any amount of information or persuasion will motivate them to change their decision (Meszaros et al., 1996). The response by health care professionals that the participants of this study described suggests attitudes and behaviors that were somewhat unexpected in that they have not been addressed within the body of immunization literature. In this discussion, I will consider such attitudes within the context of health care relationships theory, not in the interests of explaining why parents choose not to immunize, but rather, because they seem of paramount relevance to our understanding of the impact that relationships with health care professionals can have in the parental experience of choosing not to immunize.

Several themes arose from the data analysis and have been articulated as study findings. My intent in this chapter is to locate these study findings within a

broader body of literature, considering three main ideas that underpinned many of the points brought forward in this study: parental expertise, trust, and communication and power. First, I will discuss parental expertise since existing literature on immunization decision-making suggests that parents are ill-informed about immunization and disease, and are therefore making decisions with inadequate knowledge. Findings of this study seem to suggest an alternative perspective. It is my contention that examining decision-making regarding health care for children will illuminate similarities in the experiences of parents that can be applied across different contexts, including immunization. Secondly, the influence and importance of trust as experienced by parents in this study will be explored by examining existing theories on the role of trust in health care relationships and specifically with parents making health care decisions for children. Thirdly, communication and power in the health care relationship will be explored. Studies considering communication and its impact on health care decisions and health care decisions by parents will be discussed in order to inform our understanding of parental health care decision-making in immunization.

Parental Expertise and a Decision not to Immunize

Parents in this study seemed to be very well-informed about immunization and the ramifications of a decision not to immunize. All of the participants reported having read and researched extensively on the subjects of vaccine and immunization and made the decision not to immunize only after they perceived themselves as well-informed. Parents sought information which presented the

facts on both sides of the issue, although reportedly, it was difficult to find. They found themselves having to sift through opposing views and undertake substantial amounts of research to inform their decisions. Parents reported utilizing media sources to obtain information and similar to Shawn and Gold's (1987) and White and Thomson's (1995) findings, these sources appeared to play a significant role in their immunization decision-making. In addition, these parents repeatedly sought information and advice from health care professionals in order to assess the information they were obtaining from other sources.

The task of obtaining information and advice from health care professionals was reportedly made difficult by the resistance of health care professionals to discuss the topic openly or consider the evidence which parents had obtained. Like in Jerrett's study (1994) of parents coming to know the care of chronically ill children, parents in this study developed comprehensive knowledge or expertise and seemed well-prepared to assess the *expert advice* of health care professionals. Unlike existing literature suggesting that parents are uninformed, misinformed, or avoid immunization for misguided reasons (Blair et al., 1985; Grant et al., 2003; Halperin, 2000; Prislín et al., 1998; Woodruff et al., 1996), parents in this study demonstrated expertise and weighed the evidence for and against immunization very carefully before settling on a decision.

Parents in this study gathered information as one way to gain control over the uncertainty and anxiety that they experienced about immunization. Using systems theory as a framework to examine the amount of control that parents of children with chronic illness wanted over their child's care, Balling and McCubbin

(2001) found that information gathering can be seen as part of a feedback loop; when information is not forthcoming, anxiety increases and parents begin information gathering. Parents in this study reported that initially they expected to get the necessary information about vaccine and immunization from their health care professional, but when it was not made readily available to them, they experienced uncertainty and anxiety and began their own information search. As Balling and McCubbin argue, some of the information parents gather may temporarily assuage their fears. However, the primary purpose of the information gathering was to prepare the basis for communication with health care professionals. Parents hoped that if they were willing to share information they had gathered with health care professionals then health care professionals would be willing to be more open and forthcoming with information they possessed (Balling & McCubbin). Some parents in the current study did experience willingness on the part of health care professionals to share information. Unfortunately, most of these parents reported that many health care professionals were reluctant to consider or even acknowledge the information that they had obtained. This apparent reluctance to consider the parent's information generally seemed to lead to questions about the credibility of health care professionals and dissatisfaction for parents.

Most of the parents in this study described frustration when health care professionals did not acknowledge the value of parents' information and knowledge about immunization and vaccines. Parents expected to have the opportunity to discuss their information with health care professionals while being

afforded respect and consideration. On the contrary, what they described was a climate of resistance and judgment from health care professionals, as well as family and friends. The experience of having their desire to be well-informed go unrecognized and being treated disrespectfully resulted in distrust of health care professionals' and others' advice and behavior. The expectations and experiences of parents in this study were very similar to those of parents with children in hospital with regard to expertise. Studies indicate that in hospital settings parents are often asked to surrender their care giving role and find that their expertise goes unrecognized by health care professionals (Balling & McCubbin, 2001; Leahey & Harper-Jaques, 1996; Robinson, 1985). Leahey and Harper-Jaques reported that failure of health care professionals to recognize parental expertise and incorporate it into the plan of care may foster a climate of distrust, an experience also reported by parents in this study. In addition, parents in this study began to utilize strategies such as avoidance and silence to mediate the types of reactions they experienced from health care professionals and others. Thorne and Robinson (1988) also reported that their informants withheld certain kinds of information such as alternative treatment that might engender disapproval from health care professionals.

Parents reported that they took the time needed to make what they perceived was the right decision. Although parents struggled at times to obtain the necessary information to make an informed decision, these parents did not seem to succumb to what they perceived was pressure from health care professionals and others to make a hasty decision. This finding was similar to the

findings of Angst and Deatrick (1996) who reported that families who saw alternatives did not make decisions quickly. Parents in this study also valued the opportunity to make the decision themselves and not rely on health care professionals or others to make the decision for them, although they described the decision as difficult and the experience as isolating. Goldman (1995) asserted that resentment is generally greater when a decision is made for an individual by someone else, even if the person was well-meaning. The reports of parents in this study seem to be similar to Goldman's theory in relation to decision-making which indicate that parents prefer that decisions should be left to the individual since they understand their own values. In addition, frustration and hurt were evident when health care professionals and others tried to make decisions for parents or communicated dissatisfaction with parents' decisions.

No studies were found that examined decision-making of parents regarding immunization, but models of parental decision-making in other contexts are available that inform this discussion. For example, Dixon (1996) described four patterns of decision-making which characterized the changing relationship between parents and professionals in chronically ill children. Decision-making that was professional dominated refers to a pattern in which parents deferred to the professionals due to high trust and the initial feelings of being overwhelmed. Participatory decision-making occurred as parents became more active in decision-making and although parents usually agreed with decisions recommended by professionals, they began to see their own role as important. Challenging decision-making occurred when the balance of power began to shift

to the parent who now had extensive information and this pattern was characterized by questioning health care professionals. Collaboration or the taking charge pattern of decision-making occurred when parents were self-confident, assertive, and became aware of their personal power. This pattern allowed parents to approach professionals as equals.

Parents in this study were aware very early in the parenting role that immunization was a controversial and emotionally charged issue. Some parents had approached the issue with health care professionals prior to the birth of the child and all of the parents seemed to have already taken a stance which would preclude professional dominated and participatory models of decision-making. Most of the parents initially used challenging decision-making since they were gathering extensive information and developing expertise on the topic of immunization. Some parents in this study moved to collaboration, and others simply avoided health care settings since the decision-making relationship was too difficult or frustrating.

Parents in this study also demonstrated confidence in relation to being well-informed and making the right decision. Confidence is defined as "the fact of being or feeling certain (Webster, 1976)." Confidence was described by Thorne (1993) in relation to health care relationships in chronic illness. Thorne stated that with extensive time in the chronic illness experience and dedication to learning about their illness and its management, patients and families could become sufficiently confident to take on the responsibility of managing their own health care. Similarly, these parents demonstrated dedication to learning about

immunization and vaccine and became sufficiently confident to take on the responsibility of making immunization decisions. These parents expressed confidence in the decision which they ultimately made regarding immunization.

It was evident from parent's descriptions of the information that they gathered and the resources that they utilized, that making a decision about immunization was not taken lightly or done hastily. These parents weighed all of the options and issues and made a decision which they perceived was the best one for the welfare of their child. In addition, parents reported that they felt confident about their decision and they perceived that additional information would have been unlikely to change their decision. Trust was an integral part of the experience which these parents described in determining the value of the information and advice that they obtained while attempting to make an immunization decision. Therefore, the next step is to specifically consider trust.

Trust in Varying Degrees

Parents in this study initially expressed trust that they would be supported with information and direction in the process of making an immunization decision. Their initial expectation of health care professionals was that information and advice given would be in the best interest of their child. Some parents were successful in their initial attempts to gather information but, other parents very quickly began to experience frustration at the difficulties of accessing and gathering information. Most of the parents reported tension and dissatisfaction when they began to perceive that information was being withheld because health care professionals were towing the party line or maintaining the status quo.

Parents also reported dissatisfaction when they perceived that information was being withheld because the information was not consistent with the recommended standard of care. Parents expressed mistrust of big business and the medical establishment in relation to immunization messages provided to the public. Similar to White and Thomson's (1995) findings, these parents were suspicious of government policies, believing that promotion of immunization was motivated by a political agenda. Parents were also skeptical of medical and scientific information, a finding also reported by Meszaros et al. (1996).

Some of the parents perceived that some health care professionals were promoting immunization in order to maintain the status quo or because of peer pressure. They reported that it was difficult to determine if a health care professional's motives for a pro-immunization stance were genuine concern for the child's welfare or motivated by other loyalties. Some parents viewed health care professionals suspiciously and felt that the health care professionals' support for immunization was influenced by pharmaceutical company sources of hospital funding. Mistrust also arose from a belief that health care professionals did not approach the subject of immunization with critical thought but, rather, that their opinions resulted from indoctrination or the medical establishment being unwilling to examine alternatives. Parents repeatedly expressed a desire to avail themselves of the expert advice of health care professionals but the political and emotional nature of the issue put the truth or value of the advice in question. The mistrust that was suggested by parents in this study should be considered in light of the growing mistrust of the medical system in general. It is possible that trust in

health care professionals may not be solely dependent on a health care professional's individual approach to immunization, but rather, may depend in part on their belonging to the medical system.

Parents in this study felt that their decision to not immunize was under constant scrutiny by health care professionals, family and friends, and that they had to repeatedly justify their decision. Some parents expressed their discomfort when health care professionals and others were not in agreement with their decision. As a result, some parents adopted behaviors to cope with the discomfort they anticipated. For instance, similar to parents in Thorne and Robinson's (1988) study which examined trust in health care relationships, parents in this study exhibited selective information-giving, whereby they withheld certain kinds of information (in this case, about immunization choices) that they felt might engender disapproval from health care professionals.

Trust has been found to be an important component of satisfying, effective health care relationships and its importance has been demonstrated in health care relationships of hospitalized children, chronically ill children, and chronically ill adults (Balling & McCubbin, 2001; Dixon, 1996; Thorne, 1993; Thorne & Robinson, 1988). Models of understanding trust and trust breakdown in the illness context may be helpful in understanding the phenomenon as it applies to these parents who make a decision not to immunize because while the experiences of parents of chronically ill children may be different from those of well children, all parents must still enter into a health care relationship with providers in order to obtain services from the health care system. Dixon reported

that “parents’ appraisals of providers’ trustworthiness and their conscious decision to trust the professionals who were caring for their children were based on the assumption that professionals would interact with them in a positive, reciprocal manner” (p. 117). Likewise, parents in this study indicated that trust was also an important component for satisfaction in ongoing health care provider relationships where no illness state exists since these parents did not remain in health care relationships unless the interactions were positive and trustworthy. Parents in this study reported disappointment when health care professionals did not interact with them in a manner which they would describe as positive or demonstrative of mutual trust.

Thorne’s (1993) model of health care relationships may help to explain some aspects of trust in the experience of parents choosing not to immunize. Thorne described three stages in a process of health care relationships: naïve trust, disenchantment, and guarded alliance. Thorne reported that initially patients and their families tended to demonstrate “naïve trust” (p. 84) in health care professionals. Parents of chronically ill children entered their early health care relationships with the assumption that the health care provider would have their child’s best interests in mind and would initiate whatever was necessary to facilitate those best interests (Thorne). Parents in this study, in the early stages of the parent-professional relationship, believed that the health care provider would demonstrate concern for the welfare of their child and address concerns that they had (in this case about vaccine and immunization) to facilitate the best health care for their child.

Thorne (1993) reported that for her informants, naïve trust was shattered early on for some, and for others, the trust endured for some time into the experience. For parents making a decision not to immunize their child, naïve trust tended to be short-lived. Indeed, some parents were already questioning the trustworthiness of their health care provider before their child was born. Once parents began to explore the issue of immunization and shared that information with their health care providers it was quickly evident that most of the parents held different interpretations or beliefs than their health care professionals. For some parents, it seemed that naïve trust concluded when health care providers were reluctant to discuss parent's findings or entertain parent's questions. As such, many parents did not get an opportunity to critically consider the information they had with their health care professionals. Most often parents chose to believe and follow the recommendations of the information they themselves had obtained since the health care professionals' reluctance to consider the information resulted in the parent questioning the health care professional's trustworthiness.

Thorne (1993) suggests that disenchantment in the health care relationship begins when an uninformed and trusting stance is no longer tenable due to events which had occurred in the parent-provider relationship. Similar to the disenchantment described by Thorne, parents in this study also seemed to feel disenchanted, particularly when they perceived health care providers to be reluctant to consider information they had obtained. Parents reported that health care providers were reluctant to answer questions raised by information parents

had obtained, were critical of parental information sources, utilized information sources not acceptable to parents, such as pharmaceutical company funded research, and were unable to knowledgeably refute parents' understanding of the issue. For other parents, as noted by Thorne, the transition into disenchantment was not precipitated by a single event. Some of the parents in this study simply began to realize that their perceptions differed from those of mainstream health care. Similar to Thorne's description of the feelings associated with the transition into disenchantment, the majority of parents in this study shared a common experience of the transition into disenchantment as a time of frustration and self-doubt. These parents expressed disappointment and frustration that their health care providers were unable, and at times, even unwilling to engage in critical reflection of the opposing views. In addition, parents sought more and more information in an attempt to be well-informed but also to cope with their feelings of self-doubt. They found themselves asking questions such as: Am I doing the right thing? Am I harming my child? Am I a bad parent or an irresponsible parent? Parents were inevitably disillusioned by health care professionals in whom they had placed their trust but who seemingly had a limited grasp of the information and failed to act in a way that was indicative of concern for the welfare of their child.

Guarded alliance, the third stage of health care relationships described by Thorne (1993) occurs when naïve trust and profound confusion are replaced by a new understanding of how the parent's own experience might fit into the larger picture of health care delivery, and the stage in which parents employ strategies

to make sense of and manage their health care relationships. Although parents making a decision not to immunize may become "guarded," most parents did not form an alliance. Some parents seemed to stay entirely "disenchanted" and angry or frustrated, especially if they found satisfaction from another health model, system or practitioner. Unlike parents in a chronic illness experience, these parents had the option of avoiding relationships which they did not find helpful or trustworthy. For many of the parents, they no longer sought information or opinions about vaccine and immunization from health care professionals who were not supportive of their perspective. Parents tended to discuss their views and opinions with likeminded friends, family, or health care practitioners.

Several of the parents in this study had been open and honest with health care providers about seeking someone who would not judge them negatively or take an adversarial approach toward them based on their decision not to immunize. Parents in this study also set limitations on health care encounters, for example: utilizing the services and information available from public health for issues other than immunization or vaccine; accepting treatments only after discussing the necessity in detail; and requesting references for information provided by physicians if the information or the source was not clear to the parent.

Parents choosing not to immunize seemed to progress through some of the same processes as parents of chronically ill children. A key difference seems to be that parents making immunization decisions can opt out of a health care relationship at any time and seek information, guidance, and health care

elsewhere. This examination of trust in health care relationships has the potential to inform health care professionals in their interactions with parents choosing not to immunize both in understanding the parental response to the health care professional and also in how to support the parent. Considering the accounts of the parents in this study, it seems apparent that health care relationships are an important factor in their experience of making decisions about immunization.

Communication and Power in Health Care Relationships

It is important that we attend to issues such as communication and power in the health care relationship since they seem relevant to the experience of these parents. The importance of effective communication in the health care relationship of parents choosing not to immunize was gleaned by attending to parents' descriptions of several facets of communication. Parents in this study expressed a desire for open and timely information sharing, and expressed satisfaction when that occurred. Parents expressed positive regard for health care professionals who they perceived to have the desired knowledge and were able to see the parent's point of view. In addition, parents felt supported when health care professionals were knowledgeable about immunization, and questioned immunization, even if the health care professional did not share the parents' perspective. Having support from health care professionals who were open to discussion and questions seemed to be an important factor in facilitating parental satisfaction.

Parents appreciated encounters with health care professionals in which they felt respected. In addition, parents expressed a desire for acknowledgement

that the decision was made with the best of intentions and not with disregard for the child's well-being. Parents expressed concern that they would be judged on their parenting decisions based on a decision not to immunize. Parents demonstrated reluctance or a lack of freedom to ask questions while seeking information. Parents prior experiences with health care professionals seemed to influence the freedom they felt to ask questions. The findings of this current study also support the findings of Bond and colleagues (1998) who reported that health care providers who dismissed parents' questions and concerns contribute to beliefs that the parents' role in the decision to immunize was not treated seriously.

Parents reported frustration when they perceived that only portions of the available information were offered and only those which supported the policy expectations regarding immunization. In addition, parents reported that they had to make repeated attempts in order to access that information. Parents perceived that health care professionals were not open to being questioned about immunization and were not allowed to question immunization themselves. Health care professionals' resistance to listen to parent's information negated the value of the health care providers' information for some parents. Parents recounted overtly adversarial encounters which prevented any productive communication between parent and health care professional and left some parents feeling that health care professionals were no longer a resource for their family. The findings of this study demonstrate that open communication and the willingness to share information are important to parents, as was similarly described by Balling and

McCubbin (2001).

Mutual participatory communication refers to communication which occurs between parents and health care professionals where the expectation is that both parties contribute to the dialogue in a joint manner (Szasz & Hollander, 1956).

Thorne (1993) found that the trustworthiness of health care professionals depended on a combination of competence and communication skills. Active listening was among the most important communication skills described by Thorne's informants. Similarly, parents in this study described a variety of ways in which active listening was important to their experience of feeling supported and understood. Findings from this study suggest that encounters with health care professionals were more satisfying for parents when they felt listened to and their views were taken into account. For instance, parents were impressed by professionals who took the time and were able to explain difficult concepts to them in a respectful, yet understandable manner. Thorne makes the connection between competence, communication and trust when she states that without a positive communication style such as active listening, competence was considered insufficient for trust. In addition, a health care professional's competence was perceived as worthwhile only if the professional had the time or inclination to communicate effectively. Several parents in this study described health care professionals who they perceived as experts based on the individual's willingness to share information or opinions articulately and yet simply. Other parents described health care professionals as not being willing to listen which left parents feeling frustrated and unwilling to consider the health

care professionals advice or expertise.

Disruption of the traditional balance of power¹⁵ within the health care relationship which occurred when a parent questioned immunization and ultimately chose not to immunize their child was also a factor in the experience of some parents. Over the past forty years, the relationship between health care professionals, patients, and family members has been addressed repeatedly in the literature. Studies report that there has been a transition away from relationships in which health care professionals are the experts and clients are passive recipients of care (Biley, 1992; Dixon, 1996; Haug & Lavin, 1981). Authors have described the development of mutuality between clients and health care professionals (Szasz & Hollender, 1956) and the client as consumer (Reeder, 1972). For the purpose of this discussion, the parent will be understood as the patient within the relationship as much of the available literature uses the language of patient-professional in order to address this dynamic.

Emanuel and Emanuel (1995) outlined four models of physician-patient interactions (paternalistic, informative, interpretive, and deliberative) which may help explain some of the experiences that parents described in this study. According to Emanuel and Emanuel, paternalistic interactions encompass those where health care professionals select information that encourages consent for the intervention the health care professional considers best, assuming that the health care professional can discern what is in the [parent and child's] best interest with limited parent participation. The health care professional's emphasis is on health and not choice. In the informative model, the objective is for the

15 Power in this context refers to authority, ability to control or influence others.

health care professional to provide the patient with all relevant information, for the patient, in turn, to choose the desired interventions based on his or her own values, and for the health care professional to provide those interventions. In the interpretive model, the health care professional attempts to determine the patient's values and assist the patient to choose interventions that best realize these values, neither dictating the best course of action nor judging the patient's values. In the deliberative model, the aim is to help the patient choose the options with the best health-related values. The health care professional acts as teacher or friend and engages the patient in dialogue with the objective of discussing why specific health-related values are worthy of consideration.

All parents in this study reported interactions which could be considered paternalistic. Some parents reported being told that there was nothing to discuss, there was no decision to make, and immunization was just what was done when you had children. When parents attempted to discuss their decision, some felt that health care professionals provided very limited information which was exclusively pro-immunization. In addition, parents found health care professionals were reluctant to discuss the immunization literature or their criteria for making a recommendation to immunize. Parents also claimed that some health care providers attempted to use scare tactics and intimidation such as describing worse-case disease scenarios to describe why immunization was best. A few parents did report experiences with an informative model in which they were provided with information and allowed to weigh the options in light of their own values. However, most parents reported that their values were usually

not respected or given consideration. All of the parents in the current study expressed a desire to be provided with all available facts by health care professionals, but in actual practice, perceived that information was withheld and usually not offered or easily obtained.

Parents in this study who sought alternative health care approaches, such as strengthening the immune system rather than immunizing, reported experiences that seem to fit the interpretive model. These parents did not feel judged. Rather, these parents reported that solutions and interventions were suggested by these alternative health care practitioners which were in keeping with their values. A few parents reported interactions with health care professionals which could be described as deliberative. These parents reported that alternative health care professionals identified disease caused by wild-virus¹⁶ and a strong immune system as health-related values which should be considered valuable by parents, whereas, conventional health care professionals held immunization and the absence of vaccine-preventable disease as valuable.

The four models of interaction described by Emanuel and Emanuel (1995) embody several concepts which have evolved as issues in health care debates. For example, in recent decades there has been a focus on patient autonomy conceived as choice or control over medical decisions. The shift toward the business model for health care has resulted in patients being considered clients or consumers. With increasing concern about the legal and moral expectations of informed consent standards, the health care provider is required to provide facts

¹⁶ Wild-virus refers to disease caused by virus in its natural state unlike viruses present in vaccine which are attenuated or killed.

to empower the patient to use his or her values to determine what interventions should be implemented. It was evident from parent's descriptions of health care providers' behavior that parents experienced health care relationships which fit each of the four models. Further research is needed to explore how each model may have influenced parent's experiences, although, it is possible from the nature of the parent's descriptions, to make some initial observations.

Health care relationships, in which the use of the interpretive model was evident, were described by parents in the most positive terms. Parents were assisted in weighing their values and choosing interventions which were neither dictated nor judged. This model of health care relationship required an effective communication style and a balance of power. The use of the informative model was also potentially positive, but in fact, parents generally reported that they did not receive all relevant information which tended to lead to frustration and resentment on the part of parents. In the experience of these parents, ineffective information sharing negated the positive potential of the informative model.

The paternalistic model was reported by parents as the least satisfying in keeping with existing findings, possibly the result of the perception of inadequate information sharing, ineffective communication, an imbalance of power or a combination of these factors. Parents described interactions in which they stopped listening to the health care professional because the health care professional was assuming the authority role and ignoring the parent's perspective. Emanuel and Emanuel (1995) contend that the ideal relationship would include "a process of shared decision-making constructed around mutual

participation and respect" (p. 71), an experience rarely reported by participants. Parents in this study expressed satisfaction when health care professionals acknowledged their right to choose as the parent, based on the parent's values. They also expressed pleasure at being acknowledged as unique individuals who were not just maintaining the status quo, but making informed decisions. In keeping with Angst and Deatrick's (1996) study examining parental involvement in their children's health care decisions, parents choosing not to immunize seemed to desire involvement in their children's health care decisions and this involvement seems to be related to their satisfaction with care.

Parents who chose not to immunize expressed frustration and resentment when health care professionals hesitated to discuss the parents' views or entertain the challenges that the parents' information presented. In addition, findings suggest that some health care professionals did not take the time to understand what these parents felt was important but, rather, made recommendations based on values of prevention of disease and community responsibility. In contrast, these parents valued natural forms of disease resistance development, alternative approaches to health, strong immune systems, and avoidance of chemicals and additives. The findings of this study support Thorne and Robinson's (1988) findings, suggesting that health care professionals (as perceived by parents in this study) based their decisions on values that were distinct and even contradictory to the parent's own values. In addition, parents in this study perceived that health care professionals "did not generally understand or even care about the [parent's] perspective of his [child's]

best interest" (Thorne & Robinson, p. 783).

Summary

The discussion about health care relationships and the experience of parents who chose not to immunize highlight the importance for health care professionals to look carefully at the dynamics and effects of health care relationships on perception of health care, satisfaction with health care and possible impacts on experiences of decision-making. The study findings suggest that parental satisfaction in health care provider relationships plays an important role in developing trust. In addition, the study findings suggest that unsatisfying and ineffective health care relationships may result in mistrust, sometimes motivating parents to seek health care provider relationships outside of traditional medical models.

Self-determination regarding decisions important to an individual is a value that is strongly held in western society (Goldman, 1995). The study findings suggest that parents who chose not to immunize were unwilling to relinquish their decisions which were perceived as important to the course of their children's lives even in exchange for a higher probability of happiness or less risk of suffering. For example, parents reported that it would have been easier to maintain the status quo or follow a health care provider's advice, but they still made the decision not to immunize. Similar to Balling and McCubbin's (2001) findings, parents in this study expressed a desire for collaboration, but challenged health care professionals' advice if they perceived that the advice was not in the child's best interest. Although health care professionals may find it

much more comfortable and familiar to maintain power, parents expect that their own knowledge and ability to gather resources will be considered in the health care relationship. Findings from this study suggest that satisfaction for parents within health care relationships appears to depend on both parents and health care professionals contributing input and coming to a common understanding of the action to take. A common understanding does not prescribe that the health care professional must agree with the parent's decision, but rather, that the parent and the health care professional understand the other's perspective in the context of a plan.

These study findings seem to suggest that communication is an important aspect of the parental experience when choosing not to immunize. The findings of this study mirror those of existing studies related to other contexts in which parents make health related decisions on behalf of their children, demonstrating that a parental decision about immunization is not unlike other parental decisions and the impact of the health care relationship can be paramount to how parents perceive the experience (Angst & Deatrick, 1996; Balling & McCubbin, 2001; Gibson, 1995; Jerrett, 1994). In addition, the findings of this study suggest that the opportunity exists for health care professionals to positively influence the parental experience of both the health care relationship and the decision-making experience.

In keeping with existing studies of the impacts of communication on the health care relationship (Balling & McCubbin, 2001; Bond et al., 1998; Thorne, 1993), the findings of this study suggest that some parents experience support

and feel understood, thereby reducing anxiety and increasing satisfaction when information is shared in a timely and open fashion. The current study supports the findings of Klein and colleagues (1989) who concluded that there are deficiencies in explaining immunization on the part of health care professionals, and Blair and colleagues (1985) who reported that a lack of effective risk communication with parents regarding immunization results in doubt and misconceptions about disease. Although it is reasonable to expect that the deficiencies or lack of effective risk communication would impact parental satisfaction, the conclusion that the deficiencies result in a decision not to immunize are not supported by this study. Parents in the current study reported that health care professionals did not discuss or answer parent's questions to the parents' satisfaction. However, these parents pursued other avenues for information and made the decision based on what they perceived was a well-informed perspective. So, contrary to existing literature, this study seems to suggest that parents in this study made a decision not to immunize because they had decided, from a well-informed perspective, that not immunizing was the best choice for their child. In addition, the findings of the current study seem to indicate that: the immunization decision is a difficult decision for parents, parents seek to be well-informed, and parents experience emotional turmoil in trying to make the decision.

Previous studies indicate that there has been a shift in the traditional balance of power within health care relationships (Biley, 1992; Dixon, 1996; Haug & Lavin, 1981). Parents in this study expressed satisfaction when their right to

choose as the parent was acknowledged and their values were considered important factors in the health care equation. Recent health care debate introduced the concepts of consumerism, obligations of the health care provider, and the client's right to be fully informed. Parents in this study developed expertise and confidence and were, therefore, unwilling to allow health care professionals to make health care decisions without their express input. The parents in this study, similar to those in the Jerrett (1994) study examining the experience of parents coming to know the care of a chronically ill child, were able to challenge the widely held assumption that the family is a passive recipient of 'expert' advice.

Chapter 6

Implications for Nursing

The intent of this interpretive descriptive study was to examine the experiences of parents who chose not to immunize their children. Little research had been done to explore and gain understanding of the perspective of these parents. Findings from other studies suggest that typically, it is assumed that parents choosing not to immunize were either ill informed about the benefits of immunization or the potential consequences of their decisions. Although some parents may have drawn upon somewhat different sources of information, or may have interpreted scientific evidence differently than is the dominant understanding among health care professionals, the level of information among parents in this study was quite high, and parents had clearly engaged in active searching for alternative understandings to make sense of the information to which they had access. Parents in this study described experiences with health care professionals that left them feeling judged and misunderstood. From the parents' perspective, they often felt judged by health care professionals, family, and friends against a shared standard of "reasonable behavior" and, as a consequence, some parents felt that they were the recipients of emotional arguments, bullying and hostility.

The findings of this study revealed that some parents initially grappled with the question of immunization resulting either from questions they had regarding impending parenthood or due to their own educational pursuits which led them to question traditional forms of health care. Parents sought information from a

variety of sources in their quest to be informed, and many found that information was difficult to obtain and often one-sided. These parents found themselves trying to make a difficult decision within a context in which immunization of children was considered the status quo. The parents' quest to make an informed decision and the oftentimes judgmental attitudes of health care professionals, family, and friends, left some of the parents feeling unsupported. The experiences recounted by these parents illuminate the need for interventions which: 1) provide opportunity for parents to ask questions as they grapple with the question of immunization; 2) support parents as they work to become well-informed; and 3) acknowledge the emotional turmoil of trying to make an immunization decision.

Implications of the Study

Parents in increasing numbers seem to be making decisions to not immunize their children (Health Canada, 2002a). The recent focus on SARS¹⁷ virus dominated the press and public anxiety about viruses and communicable diseases and the appropriate balance between public health policy and individual decision making. In this context, it is imperative for nurses to understand what parents experience when they make such a decision and for nursing to respond in meaningful and constructive ways. This study has the potential to contribute to a beginning understanding of the perspectives of these parents as well as identify the need for interventions that could support these parents. It is not my intent to identify interventions to decrease the number of parents refraining from immunization. Rather, my intent here is to recommend strategies to allow parents

¹⁷ SARS is an acronym for Sudden Acute Respiratory Syndrome.

to make a decision in the context of an effective health care relationship.

Although I acknowledge that the small sample size will limit the magnitude of the implications able to be drawn from the findings, implications which derive directly from the findings will be discussed related to nursing practice, education, research, and policy/program development. In addition, implications which derive from my perspective and opinions that have been gained through existing literature and extensive practice experience in public health will be discussed.

Implications for Nursing Practice

Study findings suggest that parents need to be able to trust or believe in the health care professional's expertise based on their demonstration of knowledge, willingness to seek answers, or critically question alternative perspectives. For parents who are seeking information about immunization, accurate information from health care professionals is crucial. The health care provider must be genuinely knowledgeable about immunization since parents making an immunization decision tended to be well-informed and, similar to Waterworth and Luker's (1990) findings, will not tolerate half thought-out explanations from health care professionals, including nurses. The use of effective and respectful communication with parents enhances learning and increases the chances of the parent benefiting from the health care professional's advice (Pantell, Stewart, Dias, Wells, & Ross, 1982).

As Thorne and Robinson (1988) state, "it is imperative to develop the particular skills of listening with intent, curbing preconceptions, soliciting the patient perspective, and validating conclusions" (p. 788). Although Thorne and

Robinson were referring specifically to the chronic illness experience, their suggestions are helpful in framing the implications from this study. Nurses may feel that they cannot validate a parent's decision not to immunize. However, the study findings indicate that parents simply wanted health care professionals to recognize and validate the seriousness with which the parents have engaged with this decision, the complexity of the issue, and the uncertainties that inevitably arise when parents study both sides of the issue. Therefore, the nurse's role with parents choosing not to immunize may need to include validation of their struggle, acknowledging that it is a very difficult decision for some parents.

The findings of this study underscore the need for health care professionals (including nurses) to critically examine their practice and how they communicate with parents who make a decision not to immunize. For example, nurses could better serve these parents by learning how to negotiate these types of situations in a manner that is not deleterious to parents' trust. Nurses are unlikely to gain anything by trying to force these parents into decisions with which they are not comfortable. Attempting to retain positive relationships with these parents and being open to intently listening and accepting parents' perspectives may help nurses to attain trustworthy relationships with parents and thereby help to prevent parents from becoming disenchanted with the health care relationship.

Parents in this study desired to have a positive working relationship with health care professionals. Yet, at times, some parents felt as though their knowledge and expertise was minimized and that health care professionals

disrespected their opinions. As members of society and the profession of nursing, nurses are challenged to be aware of and not enable situations which would prevent a parent from reaching their full potential as a decision-maker for their child. Nurses are faced with a dilemma when parents choose not to immunize, particularly when this decision conflicts with accepted standards of child health care practice. At the same time, nurses should find ways to see beyond the perpetuation of the status quo of immunization and acknowledge parent's differing ideas and thoughts. To be in an effective health care relationship does not require that the nurse agree with the parent's decision, but only that the nurse respects the parent's right to choose. If parents were empowered by the open and timely sharing of information, opportunity to discuss their concerns, and ask questions in a non-threatening climate, it would seem that their experience of choosing not to immunize may be more positive and less stressful. Since there are no established guidelines to assist practitioners in evaluating their own communications in regard to immunization decision making, and to address any problematic areas, it could be of considerable benefit for health care professionals to examine expert communication in order to better support parents during their experience.

Study findings also have implications for public health nursing practice, in that public health nurses are frequently called upon to discuss immunization decisions. Public health nurses are placed in the unenviable position of trying to discuss immunization choices with parents while, at the same time, being acutely aware of their professional responsibility to support the provincial immunization

programs. In addition, this particular field is a moving target, with knowledge and practice recommendations changing frequently. As infectious and communicable disease knowledge continues to evolve, our understanding of the information available becomes clearer and often influences the knowledge we have to impart to the public. The public press and the interpretation of issues presented to the public can also have widespread and major impacts on perceptions of health care, such as immunization. Practice implications specifically for public health nurses that arise from this study include the need to help parents put the ideas presented by the press into context through thoughtful conversation rather than simply dismissing their concerns. In addition, public health nurses need to be increasingly aware of how public health practice impacts parents, and to foster an environment in which parents feel free to ask questions and to differ in their opinions from health care professionals. Public health practice could also be enhanced by critically considering the immunization information which is made available by public health. In addition, by providing an atmosphere which is non-judgmental, in which parents feel comfortable accessing the other services of public health after having made a decision not to immunize, without being asked to repeatedly consider their decision.

Implications for Nursing Education

The implications for basic nursing education include encouraging effective communication skills which would provide opportunity to explore different perspectives in order to include some consideration for individual perspectives in a plan of care. In terms of continuing education, nurses are encouraged to keep

abreast of new information. Considering that information is readily available to patients and their families, nurses must be conscientious to maintain their knowledge base to be able to interact with clients and families in a well-informed manner. Parents in this study desired that nurses and other health care professionals have exposure to the same information that they themselves are reading so that they can discuss the information feeling confident that the health care professional understands the issues and, perhaps more importantly, be willing to explore the issues. Therefore, it is important for nurses to demonstrate an attitude of openness to exploration of issues with health care consumers and other health care professionals. In addition, learning opportunities for nurses to critically examine how their own behaviors influence their interactions with others and could have an impact on health care consumers' satisfaction in the health care relationship.

Implications for Research

This research study provides a beginning understanding of the experiences of parents when they make a decision not to immunize. This is an important area for study for a variety of reasons such as: the increasing reality of health care as a consumer product; clients having access to a large amount and variety of information, the accuracy of which is not ensured; and ongoing vaccine development. In order for nursing to be able to respond appropriately to the trends in health care, such as immunization choices, we must continue to explore this area of study. In addition, we need to ensure that we understand parent's concerns and are able to keep abreast of changing attitudes and behaviors

through ongoing research in order to be able to work with parents as they face difficult choices. Ongoing vaccine development also means that parents have an increasing need to make choices about immunization. In addition, and perhaps more importantly, we need to describe, through research, how nurses and other health care providers can interact with parents making immunization choices to create trusting relationships and develop successful alliances.

Further study with larger sample sizes of parents making a decision not to immunize would allow researchers to describe more fully the experience of parents in order to develop interventions which would specifically address parents concerns and potentially impact the health care relationship. As well, research with parents making health care decisions for well children would help to inform practice regarding the expectations of parents in the health care relationship. Further research would provide a balanced perspective of the health care experience when parents choose not to immunize by studying the perspective of health care professionals and the interaction and communication styles used by health care professionals who interact with parents making health care decisions. Research literature reports that once parents have made a decision not to immunize, they will be unlikely to change their mind. However, the assumption found in the risk communication literature that parents who receive adequate information and opportunity to ask questions at the outset will immunize, may be correct, but further research is required to inform our understanding of this dynamic.

Implications for Policy/Program Development

Findings from this study also suggest implications for policy and program development. Current policy directs nurses to adopt the perspective that childhood immunization is the accepted standard and that health promotion and teaching should reflect this standard. The potential still exists for parents to change their mind, however, if we focus our attention on the pursuit of methods to convince parents to change their minds by refining our risk communication and providing carefully edited information, we run the risk of alienating parents further without any change in the outcome. It may be possible to impact the experience of parents if public health nurses and public health managers critically reflect on how parents are presented with the initial question of immunization, so that: 1) positive health care relationships are established and maintained, 2) parents are reassured that it is okay to express their decision once it is made, and 3) parents are invited to continue to utilize public health services after declaring a plan not to immunize. Fostering and maintaining an effective health care relationship is important because even if parents choose not to immunize, there is so much more that public health has to offer. Parents in this study expressed a desire for information to be provided which is neutral in content containing as much information as possible about the vaccine, the disease, and the outcomes of both. From these parents' perspective, public health program and policy development would need to include examination of existing information sources for neutrality and comprehensiveness while avoiding language which is perceived as judgmental.

Personal Perspectives

Taking into account the number of parents choosing not to immunize, it would seem reasonable to have a specific approach outlined for managing contact by public health professionals with these parents. It may be more comfortable for these parents to have the opportunity to develop and maintain a relationship with an individual professional rather than having to repeatedly explain and defend their decision. Parents are accessing information both for and against immunization whereas public health nurses are required to maintain a comprehensive knowledge base in a large variety of areas. Therefore, it is unrealistic to expect that every public health nurse will have sufficient expertise on the topics of vaccine and immunization to be able to discuss parents' information having already read the information themselves. However, it would be potentially effective for parents to have access to a public health nurse who has the knowledge and expertise to be able to interact with parents about the information that parents are obtaining. Thus, one of the implications is to begin to acknowledge the area of vaccines and immunization decisions as an area of expertise in public health, just as public health has acknowledged the need for expertise in the area of breast-feeding. A second implication is to identify a core group of public health nurses whose mandate it is to keep abreast of all the literature on immunization and vaccines and who then act as a resource or contact for parents choosing not to immunize, or parents who are in the process of making a decision about immunization. This approach could potentially reduce parents' frustration of wanting to discuss their information but finding that health

care professionals are unprepared or uninformed about the information that parents are accessing. In addition, such an approach could reduce the discomfort of health care professionals (which I have observed) when attempting to discuss immunization information with parents when they have a limited opportunity to explore the literature and grasp the issues and concerns of parents.

Public health professionals are encouraged to acknowledge the emotional and controversial nature of immunization decisions and critically examine how they interact with parents who are considering immunization. Based on the concerns expressed by parents in this study in regard to feeling judged, public health professionals are encouraged to avoid judgmental attitudes or communicating an intolerance that will further complicate the dynamic underlying the parental decision. Public health professionals should be encouraged to avoid health education strategies that might inadvertently draw negative attention to parents who choose not to immunize, such as referring to immunization as an example of positive parenting at school meetings or parenting groups, and should remain vigilant for those contexts within which their attempts at health promotion may be variously interpreted.

Conclusion

This study has provided an initial examination of the experience of parents choosing not to immunize their children. Elements of the health care relationship have been found to be congruent with other studies and areas unique to these parents have been introduced as new ideas. In addition, the study's findings

have highlighted the potential contribution of self-reflection and critical analysis on the part of health care professionals with regard to the manner in which their behavioral and communicative practice style may influence the experience of parents who make this particular decision. By suspending judgment as to an inherently right or wrong answer to the relative risk of immunization for any specific child, the recommendations arising from the findings of this study invite the health care professional to consider possibilities beyond that which is dominantly held as the evidence-based factual truth. The absence of such critiques means nursing runs the risk of maintaining the status quo, reinforcing patterns of power, and failing to challenge dominant ideologies operating in nursing and health care (Browne, 2000).

The assumption that parents' need more information in the context of a decision not to immunize has been preliminarily challenged. The early days of parenting can be a daunting task for some people. By describing the experiences of parents, nurses and other health care professionals may be more able to provide support to parents making or having made a decision not to immunize their child. It is also my hope that parents and families may benefit from knowledge gained from the insights of those parents who have had similar experiences to their own.

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Appendix A
Letter of Invitation to Participate

Appendix B
Demographic Information

Demographic Information

Code Number _____

1. Name _____**2. Contact Number** _____

3. Age: 19-24 _____
 25-30 _____
 31-35 _____
 36-40 _____
 41-45 _____
 45+ _____

4. Gender _____**5. Age of Child/Children** _____**6. Level of Education**

Less than high school	_____
High School diploma	_____
College diploma	_____
University degree	_____
Other: _____	

Appendix C
Interview Guide

Sample Interview Guide

Opening Remarks

As you know, I am interested in learning more about the experience of parents who have made a decision not to immunize, and your interpretation of the reactions you have experienced from health care providers and others. I think it is important to learn more about the experience of parents who choose not to immunize, so that health care providers can come to know and understand your experience. I also feel that hearing about your experience may assist health care providers in the future to be more prepared to supportive parents during immunization decision-making.

Prompts

Can you tell me about when you began to consider your immunization choices?

Was there anyone in particular you talked to about your choice before settling on it?

What was your experience in talking with that person?

Once you had made your decision, how did you feel?

Can you tell me about your experience when you began sharing your decision with others?

Family?

Friends?

Health care provider?

Appendix D
Consent Form

Your signature below indicates that you have received a copy of this consent form for your own records.

Your signature indicates that you freely consent to participate in this study.

Date: _____

Signature of Participant
